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Carers looking after an adult with an intellectual disability and behaviours that challenge: Attributions, emotional reactions and helping behaviour

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Doctorate in Clinical Psychology
University of Edinburgh
March 2020

University of Edinburgh – Own Work Declaration

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Firstly, a huge thank you to all the family carers who took the time to share their experiences of looking after their loved ones with an intellectual (or learning) disability and behaviours that challenge. There were moments in the interviews of laughter and tears, as well as honest and insightful reflections of a difficult, but loving caring role. To the carer organisations I spoke with through social media, thank you for helping me reach out to as many family carers as possible. Thank you to Dr Ken MacMahon, my first supervisor, for your help with finding a new project when the first project didn't quite work out! It's fair to say you went above and beyond. Thank you also to my current supervisor, Dr Monja Knoll, who has been a wealth of knowledge and reassurance and has challenged me to produce the best work that I can. To my clinical supervisor, Dr Sharon Horne-Jenkins, thank you for your words of encouragement and your ability to rein me in at times of need – there weren't too many I hope! Thank you also to Charlotte Smith, Research Governance Co-ordinator and Rowena Stewart, Librarian from the University of Edinburgh for all your help and support in the early stages of this thesis.

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THESIS PORTFOLIO ABSTRACT

Background: Previous studies have suggested that paid and family carers' practical responses, or helping behaviour, can influence the development and maintenance of behaviours that challenge. Therefore, it is important that we understand how best to support carers to respond in a helpful way at times of difficult to manage behaviour. This thesis portfolio comprises of two main sections. The first section involves a systematic review which utilises Weiner's Attributional Model of Helping Behaviour (1985) as a framework to explore attributions and emotions. These factors are proposed to influence paid and family carers' willingness to help a child or adult with an intellectual disability (ID) and behaviours that challenge. The second section involves an empirical study which aims to explore the qualitative experiences of family carers looking after an adult relative with an ID and behaviours that challenge. There is a lack of knowledge relating to the experience of family carers, with existing research focusing primarily on the experiences of paid carers, using quantitative methodology.

Method: The review involved a thorough search of online databases and reference lists to identify relevant articles, as defined by predetermined eligibility criteria. Fifteen articles were identified, which were synthesised and evaluated using an adapted quality rating scale. The empirical study involved conducting semi-structured interviews with nine family carers about their lived experience of caring for an adult relative with an ID and behaviours that challenge. Interviews were recorded, transcribed and analysed using interpretive phenomenological analysis (IPA).

Results: The systematic review found evidence that emotions were associated with helping behaviour, however evidence that emotions acted as a mediating variable between attributions and helping behaviour was inconclusive. There was evidence of an association between carer's optimism that the behaviour will change and the likelihood of offering help to a person, however optimism for change was not measured across studies. From the empirical study analysis, five subordinate themes emerged from the interviews; 'searching for the reason', 'negative emotions and behaviours that challenge', 'tag-team approach – stronger together, 'limited support' and 'impact of caring'. Included in this were seven subthemes.

Discussion: Studies included in the review provided, at best, partial support for Weiner's model and offered limited understanding of carer's responses to behaviours that challenge. A number of theoretical and methodological limitations of Weiner's model and of the

studies that have explored the model are described. As a result, these findings are not generalisable to real-life caregiving situations, particularly to those looking after an adult relative with an ID. This review found a lack of studies related to family carers, despite this being a population that also provide a significant amount of care and support at times of behaviours that challenge. Study limitations, implications for clinical practice and recommendations for future research are discussed.

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Thesis: 22, 522
Systematic review: 10583
Empirical project: 11,127

LAY SUMMARY

Paid and family carers provide a significant amount of support to children and adults with an intellectual disability (also known as a learning disability) and behaviours that challenge (behaviour causing risk to the person or others which can impact on quality of life). Previous research has suggested that carers' practical responses can influence the development and maintenance of behaviours that challenge. Therefore, it is important that we understand how best to support paid and family carers to respond in a helpful way at times of difficult to manage behaviour.

There have been a number of studies that have used Weiner's Attributional Model of Helping Behaviour (1985) as a framework to understanding paid and family carers' behaviour. The first section of the thesis portfolio includes an update on the research focused around this model. Specifically, this review will explore paid and family carers' beliefs about behaviour (also known as attributions), emotional reactions and their influence on carers' willingness to help a child and adult with an ID and behaviours that challenge.

Previous research which has looked at what factors can influence paid and family carers' practical responses to behaviours that challenge have focused mostly on paid carers. However, there is a lack of research looking at the experience of family carers responding to behaviours that challenge displayed by their adult relative. The second section includes a qualitative study interviewing nine family carers about their experience of caring for their adult relative with an ID at times of difficult to manage behaviour. This study is interested in knowing more about the interpersonal relationship between family carers and their relative. It is also interested in knowing more about family carer's beliefs and emotional reactions towards behaviours that challenge. This study aims to highlight carer support needs that are not always met by services and help to improve the delivery of evidenced-based interventions for behaviours that challenge. The interviews with participants will be analysed and appropriate themes identified from the data. Study limitations, implications for clinical practice and recommendations for future research are discussed.

Attributions and emotional reactions applied to helping behaviour in carers looking after a child or an adult with an intellectual disability and behaviours that challenge: A systematic review

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Key words: Paid carer; Care staff; Unpaid carer; Family; Intellectual Disability; Challenging Behaviour; Attributions

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SYSTEMATIC REVIEW ABSTRACT

Objective: Paid and family carers provide a significant amount of support to children and adults with an intellectual disability (ID). Previous research suggests that how paid and family carers respond to behaviours that challenge displayed by an adult or child with an ID can influence the development and maintenance of such behaviour. Using Weiner's Attributional Model of Helping Behaviour (1985) as a framework, this systematic review aims to explore attributions and emotions as predictive variables of paid and family carers' willingness to help a child or adult with an ID at times of behaviours that challenge. In doing so, this will help to provide an understanding of how best to support paid and family carers to respond in a helpful way to difficult to manage behaviour.

Method: Through computerised searches of the PsycINFO, MedLine and CINAHL databases, and using a search strategy specifically relating to carers looking after an adult with an ID and behaviours that challenge, 15 studies were identified. All studies were assessed using quality criteria developed by the researcher.

Results: Evidence that emotions acted as a mediating variable between attributions and helping behaviour was inconclusive. There was evidence of an association between carer's optimism that the behaviour will change and the likelihood of offering help to a person, however optimism for change was not measured across studies. These results were specific only to studies that used a written vignette-based method. Evidence for other relationships proposed in Weiner's model were found to be inconsistent.

Conclusion: Studies included in this review provided, at best, partial support for Weiner's model and limited understanding of paid and family responses to behaviours that challenge. There are a number of theoretical and methodological limitations of Weiner's model and of the studies that have explored the model. As a result, these findings are not generalisable to real-life caregiving situations. This review found a lack of studies related to family carers, despite being a population that also provide a significant amount of care to children and adults with an ID and behaviours that challenge.

INTRODUCTION

The term intellectual disability (also known as learning disability) is defined as a significantly reduced ability to understand complex information or learn new skills (impairment in intellectual functioning), a reduced ability to cope independently (impairment in social and adaptive functioning) and an age of onset before adulthood (British Psychological Society [BPS], 2015). It is recognised that children and adults with an intellectual disability (ID) are at increased risk of various mental and physical health problems. As such, these groups are three to five times more likely than the average population to engage in behaviours that may be perceived as challenging (Poppes, Van der Putten & Vlaskamp, 2010), with prevalence rates estimated at between 10% and 15% (Emerson et al., 2001; Quereshi & Aalborz, 1992).

Behaviours that challenge are defined as "*behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion"* (Royal College of Psychiatry, 2007 page 13). The focal concepts of this definition include quality of life and the physical safety of the child or adult and those around them. It is important to recognise that behaviours that challenge are not intrinsic to the child or adult with an ID, rather it is a result of an interaction between the person and their environment, and as such is largely socially constructed (National Institute of Clinical Excellence [NICE], 2015; Dosen et al., 2010).

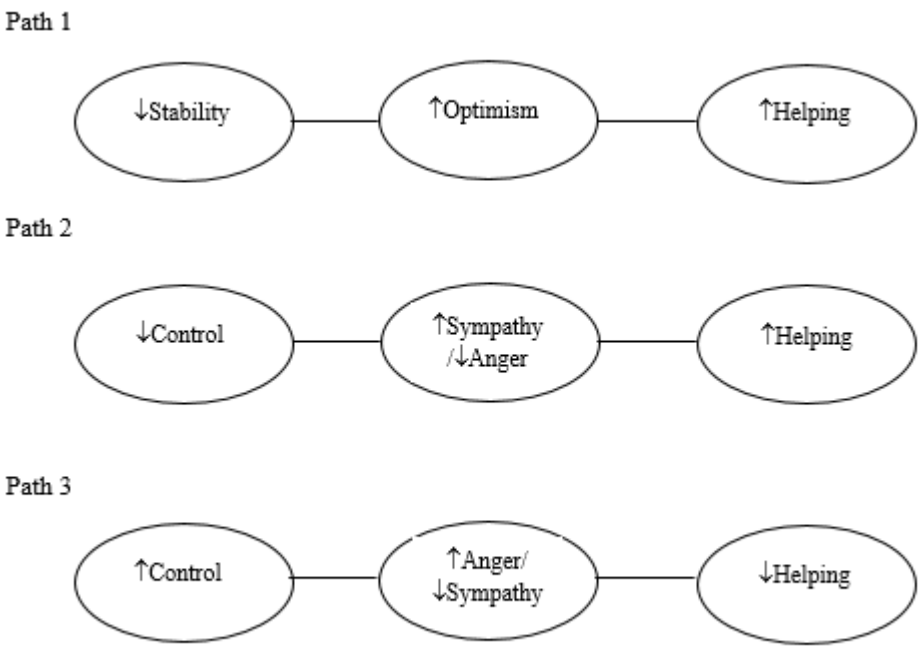
Carers provide a significant amount of care and support to children and adults with an ID and behaviours that challenge. There are two main types of carers; paid carers and family carers. According to NICE (2015, 2020), the term paid carer is used to refer to care workers or care staff in a variety of settings, including residential homes, supported living accommodation and day services. Alternatively, the term family carer is used to refer to a parent, adoptive parent, grandparent, sibling or extended family member providing unpaid care to a relative. Evidence across both carer groups, has demonstrated that looking after a child or adult with an ID and behaviours that challenge can be associated with increased levels of stress and burnout (Baker & Blacher, 2002; Hatton et al., 1999) as well as mental and physical health problems (e.g. Allen, 1999, Herring et al., 2006, Dawson et al., 2016). The elevated risk of poor mental and physical health is problematic, however, it is well documented that this can also have an adverse effect on the well-being of, and care provided to, children and adults with an ID, and consequently the development and maintenance of behaviours that challenge (Royal College of Psychiatrists, 2007; Blacher & Hatton 2007;

Hastings & Remington, 1994). Therefore, developing an understanding of the factors that influence a carer's willingness to help a person during difficult to manage behaviour is important.

Weiner's Attributional Model of Helping Behaviour (1985)

According to Weiner (1986), there are many factors that can influence whether or not someone helps another person, for example, the perceived cost and benefit to the person as well as the recipient of the help, the number of people available and the values and norms of the culture (Bailey et al., 2006). Studies have shown that carer's beliefs about behaviours that challenge are important in determining how the behaviour is perceived, understood and responded to (e.g. Bromley & Emerson 1995; Hill & Dagnan, 2002; Stanley & Standen, 2000; Willner & Smith, 2008; Dilworth, Phillips & Rose, 2011). Specifically, a substantial amount of research relating to carers in an ID setting has focused on Weiner's Attribution Model of Helping Behaviour (1985) with the following mediating pathways (or relationships) proposed (See Figure 1):

Figure 1: Three pathways in Weiner's Attributional Model of Helping Behaviour (1985)



Weiner's model describes two attributions: stability (behaviour is believed to be the same each time) and controllability (behaviour is believed to be under the control of the person

displaying the behaviour). Attributions are said to result in emotions which, in turn, influences whether an individual (e.g. the carer) then engages in helping behaviour. Carers' who hold the belief that the behaviour is under the person's control will react with anger, and will be less willing to help the person. Similarly, if the carer holds the belief that the behaviour is out with the person's control they will react with more sympathy and less anger and offer help to the person. Therefore, it is proposed that carers' beliefs about the behaviour, and not the behaviour itself, is what determines their reaction and subsequent responding behaviour. Studies have also examined carers' perceived optimism for change. For example, stability, as an attribution, has been assumed to influence carers' optimism that the behaviour can be changed, and in turn, the likelihood of carers' offering help (Willner & Smith, 2008).

Research relating to the general population support the use of Weiner's model in predicting helping behaviour (Schmidt & Weiner, 1988; Corrigan et al., 2000; Muschetto & Siegel, 2019), however the applicability of this model for carers looking after a person with an ID and behaviours that challenge is inconsistent. Willner and Smith (2008) conducted a literature review, specifically focusing on Weiner's model and whether attributions and emotions were predictive of carer's willingness to help a person with behaviours that challenge. They found only partial support for the model in an ID context. Willner and Smith (2008) argued that the variation in study outcomes were due to methodological issues, namely the reliance on theoretical rather than real-life situations to illicit carer responses, and the difficulty with defining helping behaviour. However, there are a number of limitations to consider in relation to Willner and Smith's (2008) review itself, which the present review will address.

Firstly, Willner and Smith's (2008) review did not include a clear and detailed systematic search of the literature. Secondly, a measure of study quality was not undertaken. Khan, Kunz, Kleijnen & Antes (2003) state that an assessment of quality is important for ensuring that studies reviewed employ measures to minimise bias and error in its design, implementation and analyses. Thirdly, their review erroneously included a study where individuals were recruited from an adult mental health setting and as such, the target population did not have a diagnosis of an ID (Sharrock et al., 1990). Finally, their review only included paid carers, despite family carers being a group that also provide a significant amount of care to people with an ID. In addition, since this 2008 review there have been more studies which have examined the applicability of Weiner's model to all carers of children and adults with an ID and behaviours that challenge.

Aim of review

The aim of this systematic review is to update the evidence base regarding carers' helping behaviour, ensuring that the limitations of Willner and Smith's (2008) review are addressed. Specifically, this review will address the following research question: Are the three pathways in Weiner's Attributional Model of Helping behaviour (1985) beneficial in explaining helping behaviours in paid and family carers looking after an adult or child with an ID and behaviours that challenge, within a home environment?

METHOD

An initial search of Google Scholar, the Cochrane Database of Systematic Reviews and the International Prospective Register of Systematic Reviews (PROSPERO), Centre for Reviews and Dissemination (CRD) was conducted to ensure that no recent review focusing on the same research question had been published or was currently being undertaken. This review was subsequently registered with PROSPERO (CRD42019144870) to improve transparency and reduce risk of bias. This review was written in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Statement (PRISMA, 2009).

Search strategy

The databases outlined below were searched using a predetermined strategy and search string. The databases were chosen after researching the most frequent databases used in systematic reviews concerning ID populations. A comprehensive literature search was carried out with a Librarian experienced in systematic reviews from the University of Edinburgh. The following online databases were searched; PsychINFO, CINAHL and MedLine. A date restriction was applied during this search with only studies from the date period of 1985 to 2019 included. This was to capture studies published after the introduction of Weiner's model in 1985. Reference lists of eligible studies and Willner and Smith's (2008) previous review were manually screened for eligible studies which resulted in four further studies for inclusion. Only peer reviewed journal articles were included to ensure that the highest quality of research was considered to address the review question. The impact of not including grey literature does mean that important sources of information relating to both paid and family carers may have been missed. The PICO framework was used to generate the following search terms (Schardt, Adams, Owens, Keitz & Fontelo, 2007). See Figure 2.

Figure 2: PICO framework

P **(Patient, population, problem)**	Intellectual disability [any age] Behaviours that challenge [any type] Carers [paid and family of children or adults with an ID and behaviours that challenge]	(learning disabilit* OR intellectual disabilit* OR mental* handicap* OR mental* retard*) (challenging behavio* OR problem behavio*) (staff OR worker OR carer* OR famil* OR parent*)
I **(Intervention/Item of interest)**	Weiner's Attributional Model of Helping Behaviour (1985)	(belief* OR attribution* OR model)
C **(Comparison, if any)**	N/A	N/A
O **(Outcome)**	Helping behaviour	(help*)

Inclusion criteria

The following inclusion criteria were applied:

1. Studies that include carers providing paid or unpaid care to a child or adult with an ID. This includes, for example; staff, parents, adoptive parents, grandparents and siblings.
2. Studies involving behaviours that challenge. This includes; verbal and physical aggression, destruction of property, sexually inappropriate, stereotypical or self-injurious behaviour.
3. Peer-reviewed and published studies.
4. Studies including a measure of 1) attributions, 2) emotional reactions 3) helping behaviour or behavioural responses to behaviours that challenge.
5. Published in English.
6. Quantitative studies from when Weiner's model was first introduced in 1985 to 2019.

Exclusion criteria

The following exclusion criteria were applied:

1. Studies that do not include primary data e.g. literature or systematic review.
2. Studies taking place in an educational setting. Behaviours that challenge are reported to differ in a home environment compared to educational settings (Willner & Smith, 2008).
3. Studies that focused on training, workshops or teaching sessions for paid or family carers.
4. Studies that involve the development of an assessment measure.

Data extraction and quality assessment

Following guidance from the Centre of Research Dissemination (CRD, 2010), extraction tables were used to synthesise the data in a qualitative manner focusing on the study design and key findings. The following data was extracted: authors, year of publication, aims and hypotheses, study design, method of stimuli for eliciting carer responses, outcome measures used, statistical analyses, key findings relating to the review question and the type of carer. Where possible, effect sizes were also reported. The magnitude of the effect sizes were rated, where possible, as; small size of effect (0.1 to 0.3); medium size of effect (0.3 to 0.5); and large size of effect (0.5 to 1.0). Due to the heterogeneity of the population across studies and the way in which results were reported, quantitative data-synthesis or meta-analysis were not possible. A narrative review was therefore conducted.

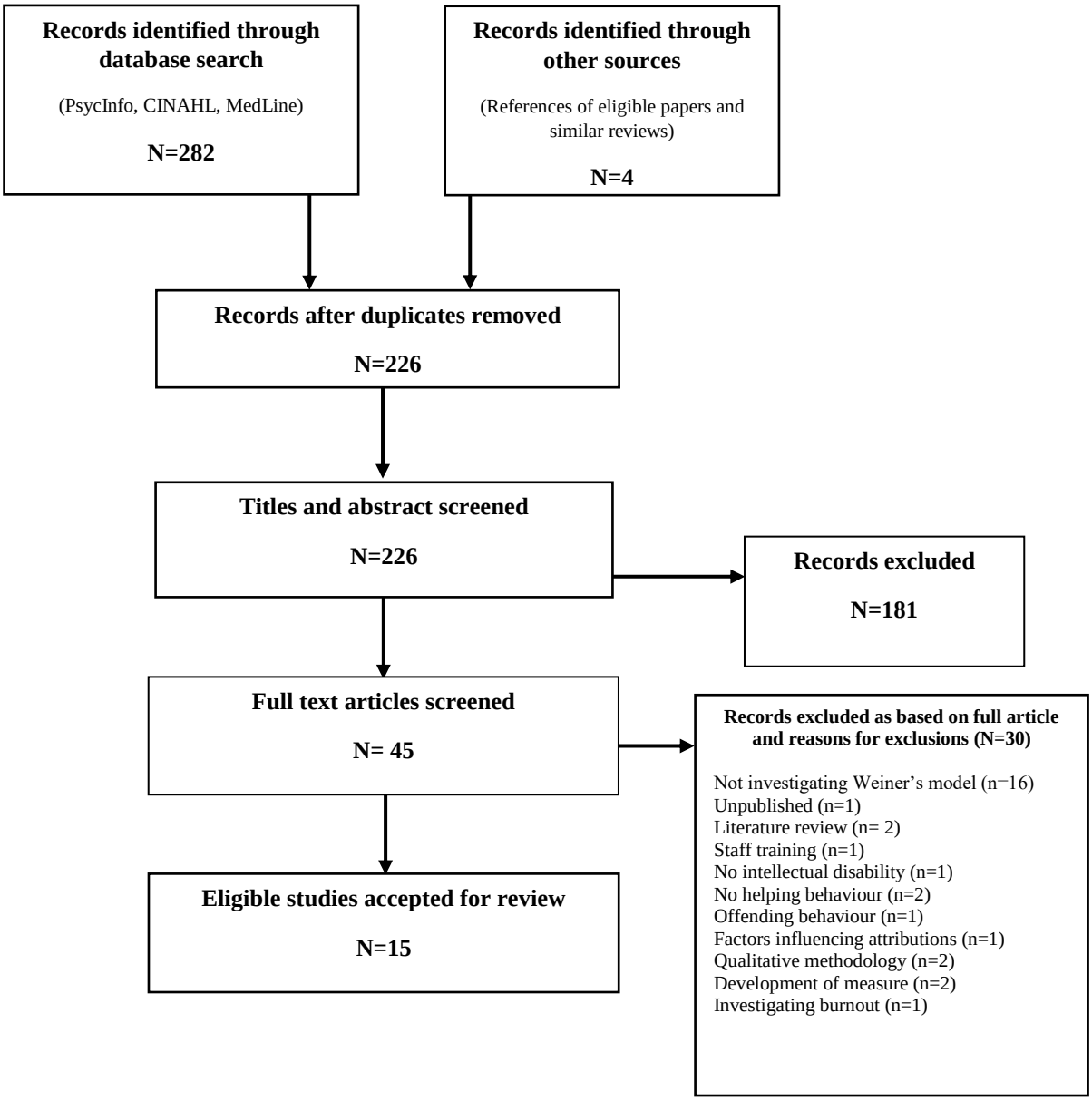
There is no recommended tool for assessing the quality of observational studies, therefore the researcher devised a tool based on a number of existing guidance, namely, Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement and the CRD (2009). The methodological quality of studies were assessed using 12 items across six criteria (study design, sample, measures used, analyses, results and limitations). See Appendix C. Quality criteria total scores were not calculated as guidance suggests that numerical scales may not account for the differential weighting of each criterion (Sanderson, Tatt & Higgins, 2007). Items were rated as ‘well addressed’ (WA), ‘adequately addressed’ (AA), ‘poorly addressed’, (PA) ‘not addressed or non applicable’ (NA). The methodological quality of each study was rated by the first researcher and a total of 6 studies (37.5%) were co-rated by a fellow Trainee Clinical Psychologist (PMI). Discrepancies were resolved through discussion.

RESULTS

Study search results

Searches yielded 282 potentially appropriate studies (see Figure 3). A further four studies were added after a manual search (n=286). Following the removal of duplicated studies using *Mendeley Reference Management Software*©, 226 studies remained. The titles and abstracts of each were then screened for eligibility, leaving 45 studies. The full texts of these studies were read and compared to the inclusion criteria. Fifteen studies were appropriate to be included in this review. See Appendix B for details of studies excluded.

Figure 3: Flowchart outlining the process and reasons for exclusion.



Data extraction

Table 1: Demographic and methodological characteristics of studies included in this review.

Author/ Study No.	Participant	Aim of study/ Pathways tested	Stimuli	Measures			Method of analysis	Key findings	Carer type
				Attribution	Emotion	Helping			
1 Armstrong & Dagnan (2006) UK	(s) Response rate: 300 letters sent to mothers. 58 (19.3%) replied of which 56 were (18.7%) interviewed. 100% female with a mean age of 39.6 (SD= 6.9). Children; 67.9% were male with a mean age of 10.7 years (SD= 3.2) ID diagnosis verified (w) Limited information on experience of CB (w) Mothers only	To apply Weiner's Attribution-al Model of Helping Behaviour (1985) relating to mothers of children with an ID and CB Path 2 and 3 tested only	**Vignette-based:** Provided with statements of CB and asked to imagine their child engaging in this way (aggression directed outward, SIB and STB)	ASQ	7-point point Likert scale of core emotions in Weiner's Model; anger and sympathy	7-point Likert scale of helping behaviour; e.g. mothers' likelihood to punish their child (w) Alternative definition of helping behaviour	Correlational and regression analysis; Mediation analysis	**Path 2:** No support **Path3:** [1]High responsibility → High anger **(r=0.28, p<0.05*)** High anger →[2]High likelihood to punish **(r= 0.52, p<0.001***)** When entered into regression equation, anger found to have a mediating effect between responsibility and punishment (w) Path 1: Optimism not assessed	Family

[1, 2] This study did not strictly differentiate between the constructs of controllability and responsibility. Willingness to help not measured and alternative definitions used. Highlights issue with definition of controllability and helping behaviour.

Author/ Study No.	Participant	Aim of study/ Pathways tested	Stimuli	Measures			Method of analysis	Key findings	Carer type
				Attribution	Emotion	Helping			
2 Chavira, Lopez, Blacher (2000) Mexico; USA	<u>Mothers</u> (n= 149), with a mean age of 40.6 years (SD= 9.6). 38% identified as single parent household <u>Children</u>: 55% male, with a mean age of 11.5 years (SD= 4.5) Mothers invited to take part by letter. 75% of interviews were in Spanish. CB was coded from interview. CB included either 'acting out' or 'deficit' (w) Mothers only (w) Wide definition of CB	To apply Weiner's Attributional Model of Helping Behaviour (1985) relating to Latin mothers of children with an ID and CB Path 2 and 3 tested only	**Real incident** (w) Definition of CB included behavioural deficits (e.g. no speech) (w) No detailed description of topography of behaviour	3-point Likert scale developed by authors. Based perception of responsibility Reliability Cronbach alpha co-efficient .75	Open-ended question as part of interview eliciting emotional reaction at time of CB. Reactions coded from transcript as 'positive', 'negative' and 'neutral'. 80% of reactions rated by 2 coders. (w) Wider range of emotions than anger/ sympathy	5-point scale of 'harshness' or aggressive behaviour in response to CB. Coded by authors from transcript	Correlational and regression analysis	**Path 2:** No support **Path 3:** Most mothers did not ascribe high responsibility to the CB displayed by their child. Of mothers who did; [3]High responsibility → High negative emotions **(r= 0.30, p<0.001**)** High responsibility → [4]High punishment **(r= 0.20, p<0.05*)** No link between emotion and punishment (w) Variety of emotions condensed into two broad categories; positive and negative affect (w) Path 1: stability and optimism not assessed	Family

[3, 4] This study did not strictly differentiate between the constructs of controllability and responsibility. Willingness to help not measured and alternative definitions used. Highlights issue with definition of controllability and helping behaviour.

Author/ Study No.	Participant	Aims of study/ Pathways tested	Stimuli used	Measures			Method of analysis	Key findings	Carer type
				Attribution	Emotion	Helping			
3 Bailey, Hare, Hatton & Limb (2006) UK	Carers (n= 27). Mean age of 40.95 years (SD = 10.33) 4 day centres with a mean length of service of 8.29 years (SD = 6.08). Carers had worked with the identified service users for a mean of 4.93 years (SD = 4.63) (s) Experience of ID and CB (w) No information regarding gender	To examine Weiner's Attributional Model of Helping Behaviour (1985) relating to staff looking after an adult with an ID and SIB To compare variables of interest with SIB and other forms of CB as measured by CCB Path 1 and 3 tested	**Real incident** Analysis of 16 carers interacting with service users identified as having "frequent" CB. Real time observation-nal data mean of 3.6 hours; range = 1.4 – 8.1 hours. (Felce & Lowe, 1999)	CHABA	ERCB 9-point Likert scale of optimism for change (w) Wider range of emotions. Depression and anger collapsed under heading 'negative emotion'. Highlights issue with exploring Weiner's model	9-point Likert scale of willingness to help Observational data coded for actual helping behaviour (s) Included actual behaviour	Planned correlational analysis	**Path 1 and 3:** No support Inverse relationship found for path 3: Low control → High negative affect (SIB only**: r=0.433, p<0.021****; Other: **r= 0.417, p< 0.006****)** Preliminary associations between helping and observed behaviour (w) Small sample size (s) Optimism assessed (w) The ERCB only measures negative emotions (w) Path 2 not tested	Paid

Author/ Study No.	Participant	Aim of study/ Pathways tested	Stimuli	Measures			Method of analysis	Key findings	Carer type
				Attribution	Emotion	Helping			
4 Dagnan (2012) UK	Carers (n= 62); 62% were female, 28% were male. Mean age of 34 years (SD= 9.3) Carers had experience working with people with an ID. Mean length of service of 8 years (SD= 8.7) (s) Experience of CB (s) Addressed CB knowledge as confounding variables using SUBIQ	To examine paid carer attributions, emotional reactions and behavioural responses to 'named' and 'unnamed' vignettes involving an adult with an ID and CB. To test out Weiner's Attributional Model of Helping Behaviour (1985) Controlled for behavioural knowledge (SIBUQ) Path 1, 2 and 3 tested	**Vignette-based:** A 'named' and 'unnamed' vignettes of someone with an ID displaying aggressive behaviour Questionnaire of behavioural knowledge (s) Clear information provided on CB	ASQ	7-point point Likert scale of two core emotions in Weiner's model; anger and sympathy 7-point scale of optimism of change (s) Optimism assessed	5-point Likert scale of intention to help	Correlational analysis; mediation analysis	**Path 1:** High optimism → High helping (unnamed: **r= -0.30, p< 0.05****) (named: **r= -0.32, p<0.001**)** **Path 2:** High sympathy → High helping (unnamed: **r= 0.39, p< 0.001****) (named: **r= 0.29, p<0.05*)** **Path 3:** High control → High anger (unnamed: **r= 0.27, p< 0.05***) (named: **r= 0.41, p<0.001****) High anger → Low helping (unnamed: **r= -0.41, p< 0.001****) (named: non-significant findings) Sobel test: High control → Low helping, mediated by high anger. Path 3 supported	Paid

Author/ Study No.	Participant	Aim of study/ Pathways tested	Stimuli	Measures			Method of analysis	Key findings	Carer type
				Attribution	Emotion	Helping			
5 Dagnan & Cairn (2005) UK	Carers (n=62). 52% were female. The mean age of participants was 36.2 years (SD= 10.9) Carers had experience of working with adults with an ID within residential and social work settings. Mean length of service was 8.5 years (SD= 8) (s) Addressed CB knowledge as confounding variables using SUBIQ (w) Limited information on experience of CB	Examining paid carers judgments of controllability and responsibility to CB and the emotional reactions and intentions to help Separated responsibility and controllability (Weiner, 1993) Path 2 and 3 tested	**Vignette-based:** Unnamed vignette of adult with an ID, aggression directed towards others by pulling hair or hitting out	ASQ plus two 7-point Likert scales of the 'responsibility for the development of the CB' and 'responsibility for changing CB' (s) Considering difference between responsibility and controllability	7-point Likert scale of two core emotions in Weiner's model; Anger and sympathy	7-point Likert scale of intention to help	Correlational and regression analysis	**Path 2:** [5]Low responsibility → High helping (r= **0.25, p< 0.05***) High sympathy → High helping (r= **0.40, p< 0.05****) Regression analysis: sympathy predicted helping behaviour **Path 3:** No link between control or responsibility, anger or helping behaviour (w) Optimism not assessed	Paid

[5] This study differentiated between the constructs of controllability and responsibility. Highlights issue with definition of controllability.

Author/ Study No.	Participant	Aim of study/ Pathways tested	Stimuli	Measures			Method of analysis	Key findings	Carer type
				Attribution	Emotion	Helping			
6 Dagnan, Trower & Smith (1998) UK	Carers (n=40). Group 1: 20 Carers working with adults with an ID and moderate CB. 50% female, with a mean age of 32.4 years (SD= 11.3). Mean length of service was 4.1 years (SD= 5.2). Group 2: 20 carers working with adults with minimal CB. 80% female, with a mean age of 35.5 years (SD= 12.2). Mean length of service was 8.4 years (SD= 7.8) Group 1 reported experience of CB. Group 1 and 2 had experience of ID	To apply Weiner's Attributional Model of Helping Behaviour (1985) relating to paid carers looking after an adult with an ID and both frequent and infrequent CB Path 1, 2 and 3 tested	**Vignette-based:** (w) No description of CB other than "example behaviour"	ASQ and a 7-point Likert scale evaluating the behaviour of the adult with an ID. 7-point Likert scale of optimism of change	7-point Likert scale of nine potential emotional reactions to CB More than two emotional reactions included	7-point Likert scale of willingness to provide extra help	Independent sample *t* tests were carried out to test for differences between the groups; correlations, path analysis and regression analysis	**Path 1:** Low stability → High optimism **(r=0.34, p<0.05**)** High optimism → High helping **(r= 0.79, p<0.01***)** **Path 2:** No support **Path 3:** High control → High negative emotion (**r= 0.52, p<0.01***)** High negative emotion → Low helping **(r=-0.53, p<0.01***)** Helping predicted optimism, optimism predicted negative emotion and negative emotion predicted control (w) Analysis based on data from both group (w) Variety of emotions collapsed into two categories	Paid

Author/ Study No.	Participant	Aim of study/ Pathways tested	Stimuli	Measures			Method of analysis	Key findings	Carer type
				Attribution	Emotion	Helping			
7 Dagnan & Weston (2006) UK	Paid carers (n= 37). 70% were female. Participants mean age was 33.9 years (SD= 9.4) Carers had experience working with adults with an ID and CB across 3 residential NHS settings. Mean length of service was 9.5 years (SD= 3.6) 35% had a formal nursing qualification (s) Detailed experience of CB	Examining type of CB and the impact on attributions, emotional reactions and the use of physical interventions to CB. The study also examines paid carers satisfaction with the intervention chosen Path 2 and 3 tested only	**First account interview** of a real-life recent incident of CB Type of behaviour was coded by authors	ASQ and a 7-point Likert scale evaluating the behaviour of the adult with an ID	7-point Likert scale of two core emotions in Weiner's model; anger and sympathy	7-point Likert scale of satisfaction with the intervention	Correlational analysis	**Path 2:** No support **Path 3:** High control → High anger **(r= 0.36, p<0.05**)** High control → [6]Low satisfaction with chosen intervention (**r= -0.60, p<0.05***)** No link between type of intervention (physical or non-physical), attributions or emotions (s) Based on real clients (w) Path 1. Optimism not assessed No role for stability or sympathy (w) Small sample size (w) Broad correlational matrix .	Paid

[6] Willingness to help not measured. Alternative definition used to better understand carers' practical responses to CB. Highlights issue with definition of helping behaviour.

Author/ Study No.	Participant	Aim of study/ Pathways tested	Stimuli	Measures			Method of analysis	Key findings	Carer type
				Attribution	Emotion	Helping			
8 Hill & Dagnan (2002) UK	Paid carers (n=33). 76% were female. The mean length of service was 10.8 years (SD=10.3) Carers had experience of working with adults with an ID. SIBUQ was administered (w) Experience of CB not reported	Examining the attributions and emotions of carers in response to CB. The study also examined coping style as a predictor of effort and helping behaviour Path 2 and 3 tested only	**Vignette-based:** Named (someone the carers had worked with) versus unnamed vignettes. Vignettes were of a person with an ID engaging in aggression and hair pulling (s) Included detailed description of CB in vignettes	ASQ	7-point Likert scale of two core emotions in Weiner's model; anger and sympathy	7-point Likert scale of intention to help Coping style was also assessed using the SWC–R	Correlational and regression analysis	**Path 2:** High sympathy → High helping **(r= 0.43, p<0.001**)** **Path 3:** Regression analysis did find that control was a significant predictor of helping behaviour (e.g. High control → Low helping No support for link between control and anger, control and sympathy or anger and helping behaviour (w) Path 1. Optimism not assessed (w) Small sample size (w) No role for emotion	Paid

Author/ Study No.	Participant	Aim of study/ Pathways tested	Stimuli	Measures			Method of analysis	Key findings	Carer type
				Attribution	Emotion	Helping			
9 Jones & Hastings (2003) UK	134 staff working in ID Services and residential settings were approached. 123 staff agreed to participate. 61.8% were female. Mean age of staff was 35.92 (SD= 9.4). Mean length of service was 48.2 months (SD=60.86) 31.9% had a formal qualification in nursing, SW or OT (s) Response rate included (w) No information about CB experience	To apply Weiner's Attributional Model of Helping Behaviour (1985) relating to paid carers looking after an adult with an ID and SIB Path 2 and 3 tested only	**Vignette based (video) unnamed** Two videos of SIB where the function of the behaviour was altered: escape maintained versus attention maintained self-injury	CDS-II Including; external and personal controllability	ERCB and a measure developed by the authors based on the ERCB to measure positive emotional reactions to CB	7-point Likert scale asking carers how likely they would to respond to the CB in the video vignette. Carers chose from a list of 14 behavioural responses (w) Alternative definition of helping behaviour	Correlational analysis (w) Broad correlational matrix not specific to Weiner's model	**Path 2:** No support. Inverse link found between High control → High positive emotions (confident/relaxed) **(r=0.26, p<0.05*).** Not consistent with model **Path 3:** For attention maintained behaviour: High control → High negative emotions (anger/depression) **(r=0.34, p<0.05**)** Escape maintained behaviour: High negative emotions → [7]High helping response that is likely to reinforce the behaviour **(r=0.28, p<0.05*)** No links between key variables means mediation analysis not possible (w) No role for stability (s) Large sample size (w) Path 1. Optimism not assessed	Paid

[7]Willingness to help not measured. Alternative definition used to better understand carers' counter-habilitative behaviour (e.g. a response likely to reinforce CB). Although this will provide relevant information within a clinical context, it highlights an issue with defining helping behaviour.

Author/ Study No.	Participant	Aim of study/ Pathways tested	Stimuli	Measures			Method of analysis	Key findings	Carer type
				Attribution	Emotion	Helping			
10 Lambrecht, Kuppens & Maes (2009) Belgium	Carers (n=51) across 20 residential settings for people with ID.94.1 % were female. Mean age of participants was 34.27 (SD= 9.71) Carers had at least 6 months experience working with The service user with an ID and CB asked about in the study (Mean; 5.97 years, SD= 4.85) (s) CB defined using BPI-II	To apply Weiner's Attributional Model of Helping Behaviour (1985) to paid carers looking after an adult with an ID and CB. Does carer response change depending on type of CB (e.g. SIB, STB and aggressive behaviour) Path 2 and 3 tested only	Real and recent incident of CB (s) Carers asked for a real description of CB over past 2 months	CHABA	ERCB	RCB (w) No information on validity of new measure (RCB)	Correlational analysis (w) Broad correlational matrix not specific to Weiner's model	**Path 2:** No support. Inverse link found between High stability → High positive emotion (confidence/relaxed) **(r= 0.28, P<0.05*)** **Path 3:** No support. Inverse link found between High control → [8]High positive interventions (e.g. offering help, calming the person down) (**r= 0.50, P<0.0001*****) High negative emotions → High positive interventions **(r= 0.41, P<0.001**).** (s) Well validated measures (w) Possible socially desirable responding (w) Path 1. Optimism not assessed (w) Alternative definition of helping behaviour	Paid

[8]Willingness to help was included in measure looking at carers' practical behavioural responses to CB. Highlights issue with definition of helping behaviour.

Author/ Study No.	Participant	Aim of study/ Pathways tested	Stimuli	Measures			Method of analysis	Key findings	Carer type
				Attribution	Emotion	Helping			
11 McGuiness & Dagnan (2001) UK	Paid carers (n=47). 59% were female. Age of carers not reported. Carers recruited from residential settings, 29 (38.3%) of which, were recruited from a specialist unit for children with ID. Mean length of service was 8.4 years (SD=6.7) (w) No information on experience of CB	To apply Weiner's Attributional Model of Helping Behaviour (1985) to paid carers looking after children with an ID and CB Path 2 and 3 tested only	**Vignette-based (written)** (w) Limited description of CB	ASQ	7-point Likert scale of two core emotions in Weiner's model; anger and sympathy	7-point Likert scale of intention to help.	Correlational and recursive regression analysis	**Path 2:** High sympathy → High helping **(r= 0.57, p<0.01***)** Sympathy is the best significant predictor of helping behaviour Control associated with helping, mediated by sympathy (low control → high sympathy → high helping) **Path 3:** High control → Low helping **(r= -0.46, p< 0.01**)** High control → Low sympathy **(r= -0.39, p< 0.01**)** (w) Path 1. Optimism not measured (w) No role for stability or negative emotions	Paid

Author/ Study No.	Participant	Aim of study/ Pathways tested	Stimuli	Measures			Method of analysis	Key findings	Carer type
				Attribution	Emotion	Helping			
12 Rose & Rose (2005) UK	150 carers were approached. N= 107 questionnaires were returned (71%). 70% female with a mean age of 35.73 years (SD = 11.05) NHS residential homes for adults with an ID. Mean length of service of 72.68 months (SD=81.04) (s) Response rate reported (s) ABC was completed to determine level of CB within homes	To investigate the impact of stress and burnout on attributions of CB within Weiner's Attributional Model of Helping Behaviour (1985) Path 1, 2 and 3 tested	**Vignette based (written)** (w) Limited detail on topography of CB in vignette (w) Unclear on whether vignettes were named or unnamed	ASQ	7-point Likert scale of happiness, sadness, sympathy, fright, disgust and relaxed Optimism for change assessed using 7-point Likert scale.	7-point Likert scale of willingness to offer extra help	Correlational analysis; Structural Path Modelling	**Paths 1, 2 and 3:** No support. Other links were found that are not consistent with the model: High stability → Low negative emotions **(r=-0.198, p<0.05**)** High optimism → High negative emotions **(r=--0.198, p<0.05*)** High control → High optimism **(r=0.196, p<0.05*)** (s) Power calculation reported (w) Helping scale not normally distributed. Not analysed (w) 7 emotions categorised into positive of negative emotions	**Paid**

Author/ Study No.	Participant	Aim of study/ Pathways tested	Stimuli	Measures			Method of analysis	Key findings	Carer type
				Attribution	Emotion	Helping			
13 Stanley & Standen (2000) UK	Carers (n= 50). 72% female with a mean age of 33.39 (SD=12.02) Mean length of service of 93.38 months (SD = 69.67) Carers were located in day services experienced working with CB. 84% reported to have occasional to continuous experience of CB (w) Does not explicitly report experience of ID, however this is assumed from topic area	To apply Weiner's Attributional Model of Helping Behaviour (1985) relating to paid carers looking after an adult with an ID an CB To compare variables of interest with other forms of CB Path 1, 2 and 3 tested	**Vignette-based** 6 vignettes based on real incidents. Type of CB was; Physical and SIB	9-point Likert scale of control, internality and stability	9-point Likert scale of negative affect, positive affect 9-point Likert scale of optimism for change (s) Optimism assessed	9 point Likert scale of intention to help	A series of two-way (2x3) ANOVAs to determine that effects of CB and dependency on control, internality, stability, negative and positive affect as well as helping behaviour Correlational analysis to examine the associations between the variables of interest	**Path 1:** No support. Inverse link found between High stability → High helping **(r=0.407, p< 0.01**)**. Not consistent with the model **Path 2:** High positive emotions → High helping behaviour (r= 0**.623, p<0.001***)** **Path 3:** High control →High negative emotions **(r= 0.398, p<0.05**)** High control → Low positive emotions **(r= -0.508, p<0.001***)** (w) Information on validity of measures missing (w) Multiple testing could be an issue with each participant completing all 6 vignettes	Paid

Author/ Study No.	Participant	Aim of study/ Pathways tested	Stimuli	Measures			Method of analysis	Key findings	Carer type
				Attribution	Emotion	Helping			
14 Willner & Smith (b) (2008) UK	121 participants total. Carers (n= 56); 57% female. Median age, 43 Care Managers (social workers or nurses=65) 69% female; median age, 38 Residential care or Community Support Team All participants had experience of looking after males with an ID and ISB (s) Response rates reported	To explore Weiner's Attributional Model of Helping Behaviour (1985) relating to staff caring for a man with an ID and ISB Path 1, 2 and 3 tested	**Vignette-based unnamed** Carers were randomly assigned to one of 4 types of vignette (non-contact or intimate contact; child or adult victim with an ID) (s) Detailed information on topography of CB in vignette (w) Not present for data collection	ASQ	5-point Likert scale of emotional reactions and optimism for change	5-point Likert scale of intention to help	Correlational and regression analysis; mediation analysis	**Path 1:** High stability → Low optimism **(r= 0.39, p< 0.001**)** When entered into regression, stability associated with helping. Found to be mediated by optimism High optimism → High helping **(r= 0.48, p<0.001**)** **Path 2:** High sympathy → High helping **(r= 0.20, p<0.05*)** **Path 3:** No support (s) Optimism for change assessed (s) Large sample size	Paid

Author/ Study No.	Participant	Aim of study/ Pathways tested	Stimuli	Measures			Method of analysis	Key findings	Carer type
				Attribution	Emotion	Helping			
15 Wanless & Jahoda (2002) UK	Carers (n=38). 13.2% of which were management 57.9% were female. Mean age of carers were 42.7 years (SD=9.67) 6 Day Centres. Mean length of service was 8.4 years (SD=5.01). Carers had experience of working with people with an ID and "frequent" CB for at least 5 months (w) Response rates not reported (s) Experience of CB verified with ABC	To apply Weiner's Attributional Model of Helping Behaviour (1985) to paid carers looking after an adult with an ID and CB To examine different methods of obtaining cognitive and emotional responses of staff Path 1, 2 and 3 tested	**Mixed:** Comparison of responses to 2 vignettes of verbal and physical aggression as well as real life recent incident of CB, adapted from a RET interview schedule (Trower et al, 1998) (s) Asked to provide detailed account of behaviour incident	Modified ASQ (Peterson et al., 1982)	7-point Likert scale of emotional reactions to CB (w) Range of emotions beyond than anger and sympathy	7-point Likert scale of willingness to provide extra support. Ratings for optimism for change and possibility of change were collected	A series of repeated measures ANOVAs to compare differences of type of CB and key variables from both vignettes and real life incidents Correlational analysis (w) Broad correlational matrix not specific to Weiner's model	**Path 1 or 2:** No support **Path 3:** High control → High anger **(real incident, r=0.45, p< 0.01**)** High control → Low sympathy **(real incident, r=0.43, p<0.01**)** Low sympathy → High helping **(r=0.37, p<0.01**)** **Other:** Inverse links found between High anger→ High helping **(real, incident, r=0.45, p<0.01**)** . High control → High helping **(real incident, r=0.45, p<0.01**)** A similar pattern was found for vignettes (w) Small sample size	Paid

Table 1 abbreviations: ID: Intellectual Disability; ISB: Inappropriate Sexual Behaviour; CB: Behaviours that challenge; ASQ: Attributional Style Questionnaire (Peterson et al., 1982); SIB: Self-Injurious Behaviour; ADL: Activities of Daily Living; CHABA: Challenging Behaviour Attributions Scale (Hastings, 1997); ERCB: Emotional Responses to Challenging Behaviour Scale (Mitchell & Hastings, 1998); CBC: Challenging Behaviour Checklist (Harris, Humphreys & Thomson, 1994); STB: Stereotypical Behaviour; SIBUQ: Self-Injury Behavioural Understanding Questionnaire (Oliver et al., 1996); SWC-R: The Shortened Ways of Coping–Revised Questionnaire (Hatton & Emerson, 1995); SW: Social Work; OT: Occupational Therapy; CDS=II: Causal Dimension Scale – Revised (McAuley, Duncan & Russell, 1992); BPI: Behaviour Problem Inventory (Rojahn, Matson, Lott, Esbensen & Small, 2001); RCB: Reactions to Challenging Behaviour scale (Lambrechts & Maes, 2006*);* SCIBI: Staff–Client Interactive Behavior Inventory (Willems, Embregts, Stams & Moonen, 2010); RET: Rational Emotive Therapy; (w): Weakness, (s): Strength; *: Small size of effect (0.1 to 0.3); **: Medium size of effect (0.3 to 0.5); ***: Large size of effect (0.5 to 1.0)

Characteristics of included studies

Table 1 provides characteristics of all carer studies. All studies were peer reviewed and used a cross-sectional or experimental design. The distribution of gender was varied, ranging between 52% and 100% female (1, 2, 5). One study (3) provided no information regarding gender. The mean age of carers ranged between 32.4 and 40.95 years. Age was not reported in three studies (8, 11, 14). The total sample number was varied, ranging between 33 and 149 participants. Two studies (1, 2) recruited exclusively family carers (mothers) and the remainder of the studies recruited paid carers with a mean length of service of between 4.1 and 10.3 years. Paid carers were reported to work in a variety of different settings; day services, residential, social work and NHS. Eight studies (3, 6, 7, 10, 12, 13, 14, 15) outlined that carers had experience of working with an adult or child with both an ID and behaviours that challenge. Seven studies (1, 2, 4, 5, 8, 9, 11) stated that carers had experience of working with an adult or child with an ID, but no information was provided regarding their experience of behaviours that challenge. The types of behaviours that challenge spoken about in all studies included a combination of; aggressive behaviour which was both verbal and physical, destruction of property, self-injurious behaviour and stereotypical behaviour. One study (14) included inappropriate sexual behaviour.

The majority of studies investigating attributions in accordance with Weiner's model have not differentiated between the constructs of controllability and responsibility. Only one study included in this review (5) investigated these attributional constructs separately. To measure attributions, two studies (3, 10) adopted the Challenging Behaviour Attributions Scale (CHABA; Hastings, 1997). Ten studies (1, 4, 5, 6, 7, 8, 11, 12, 14, 15) used the Modified ASQ and one study (9) used the Causal Dimension Scale – Revised (McCauley, Duncan, & Russell, 1992). Two studies (2, 13) utilised a measure that was developed for their study and the validity or reliability of this measure was not reported. With regard to emotions, three studies (3, 9, 10) adopted the Emotional Responses to Challenging Behaviour Scale (ERCBS; Mitchell & Hastings, 2005) and 11 studies used a traditional 7 point Likert scale, which was used in prior studies to test the key pathways in Weiner's model (1, 4, 5, 6, 7, 8, 11, 12, 13, 14, 15). Qualitative descriptions of emotional reactions and behavioural responses were coded from transcripts in one study (2). The definitions of helping behaviour across studies are varied. Weiner (1985) defined this as a willingness to help or exert extra time and effort to help a person. Nine studies used this traditional definition (3, 4, 5, 6, 8, 11, 12, 13, 14). However, there are some limitations with this definition as typically studies in this area have not asked carers what they actually *did* to help a person. This is important because carers' willingness to help a person may, in

practice, be unhelpful and lead to the maintenance of the behaviours that challenge (Jones & Hastings, 2003). In order to address this, one study included an additional measure of actual carer behaviour using observational data (3). Two studies (14, 15) measured whether positive or restrictive responses were implemented in response to behaviours that challenge and a further two studies (1, 2) measured the likelihood that carers' would engage in punitive behaviour. One study (7) measured the type of intervention and satisfaction with the carers' chosen response to better understand carer behaviour.

Table 2: Quality ratings for each of the studies relating to all carers

Author (Inc. year and study number)	Study design		Sample			Measures used		Analysis		Results	Limitations	
	Aims and hypothesis	Ethical considerations	Representativeness of sample	Participant demographics	Response rates	Method of eliciting carer responses	Quality of measures	Power calculation	Statistical analysis	Conclusion	Study limitations	Conflict of interest
1 Armstrong & Dagnan (2011)	AA	WA	AA	AA	WA	AA	WA	NA	WA	WA	AA	NA
2 Bailey et al. (2006)	WA	NA	WA	AA	NA	WA	WA	NA	AA	WA	WA	NA
3 Chavira et al. (2000)	WA	NA	AA	AA	NA	AA	PA	NA	AA	AA	AA	NA

NB: WA; well addressed, AA; adequately addressed, PA; poorly addressed, NA; Not addressed

4 Dagnan (2012)	**AA**	**NA**	**AA**	**WA**	**NA**	**WA**	**WA**	**NA**	**WA**	**WA**	**WA**	**NA**
5 Dagnan & Cairns (2005)	**AA**	**NA**	**AA**	**WA**	**NA**	**WA**	**WA**	**NA**	**AA**	**WA**	**AA**	**NA**
6 Dagnan et al. (1998)	**WA**	**NA**	**AA**	**WA**	**NA**	**PA**	**WA**	**NA**	**AA**	**WA**	**WA**	**NA**
7 Dagnan & Weston (2006)	**WA**	**NA**	**WA**	**WA**	**NA**	**AA**	**AA**	**NA**	**PA**	**AA**	**AA**	**NA**
8 Hill & Dagnan (2002)	**AA**	**NA**	**AA**	**WA**	**NA**	**WA**	**WA**	**NA**	**AA**	**AA**	**AA**	**NA**
9 Jones & Hastings (2003)	**AA**	**NA**	**AA**	**WA**	**AA**	**WA**	**AA**	**NA**	**PA**	**WA**	**WA**	**NA**
10 Lambrecht et al. (2009)	**WA**	**WA**	**WA**	**WA**	**NA**	**WA**	**AA**	**NA**	**PA**	**WA**	**WA**	**NA**

NB: WA; well addressed, AA; adequately addressed, PA; poorly addressed, NA; Not addressed

11 McGuiness & Dagnan (2001)	**WA**	**NA**	**PA**	**AA**	**NA**	**AA**	**WA**	**NA**	**WA**	**AA**	**AA**	**NA**
12 Rose & Rose (2005)	**WA**	**NA**	**AA**	**WA**	**WA**	**PA**	**WA**	**WA**	**WA**	**WA**	**WA**	**NA**
13 Stanley & Standen (2000)	**WA**	**NA**	**AA**	**AA**	**NA**	**AA**	**PA**	**NA**	**PA**	**WA**	**WA**	**NA**
14 Willner & Smith (2008b)	**WA**	**WA**	**WA**	**WA**	**AA**	**WA**	**WA**	**NA**	**WA**	**WA**	**WA**	**NA**
15 Wanless & Jahoda (2002)	**WA**	**NA**	**WA**	**WA**	**NA**	**WA**	**WA**	**NA**	**PA**	**WA**	**WA**	**NA**

NB: WA; well addressed, AA; adequately addressed, PA; poorly addressed, NA; Not addressed

Quality of studies

Table 2 includes the quality ratings for each of the studies. All studies explored Path 2 and 3 of Weiner's model, with seven studies (3, 4, 6, 12, 13, 14, 15) including an additional measure of optimism for change in order to explore Path 1. Eleven out of the 15 studies were based on a robust rationale with clearly defined aims and hypotheses (2, 3, 4, 6, 7, 10, 11, 12, 13, 14, 15). The remainder of the studies aims and hypotheses were not explicitly reported, but could be inferred from the literature (1, 5, 8, 9). All studies used convenience sampling which can result in a selection bias and pose a threat to external validity. A randomised sample would have been difficult to achieve with this group, however, this limitation was held in mind. Three out of the 15 studies confirmed that the study was subject to independent ethical approval (1, 10, 14).

The sample number was reported in all studies, however 11 out of 15 studies did not provide a response rate, which could lead to sampling bias. The response rate varied between 18.7% and 91.7% (1, 9, 12, 14). Carers in seven of the 15 studies had experience of looking after an adult with an ID, but provided limited information of their experience of behaviours that challenge (1, 2, 4, 5, 8, 9, 11). Providing this information is important because how carers respond to behaviours that challenge will vary based on their caring experience.

No single measure of helping behaviour was utilised across all studies in this review. Only one study investigated the link between 'actual' helping behaviour and willingness to help, but no association was found between these variables (3). With regard to stimuli used to produce carers' responses (e.g. actual experiences or vignette-based), ten studies were vignette-based (1, 4, 5, 6, 8, 9, 11, 12, 13, 14), of which four did not provide sufficient detail about the situation or topography of the behaviour (6, 11, 12, 13). Five studies asked for participants to recall real life events of behaviours that challenge (2, 3, 7, 10, 15) of which two had a small sample size (3, 15). This has an impact on the reliability and generalisability of their findings. There are methodological weaknesses also with using real life events, however, this approach is recognised as more ecologically valid and has been found to produce more emotive responses to behaviours that challenge (Jahoda & Wanless, 2005). Two studies (5, 14) asked participants explicitly to respond to one type of behaviours that challenge. Research has argued that categorising behaviour into a single form is unrepresentative of the ID population, as in real life, many presentations of behaviours that challenge co-exist (Qureshi, 1994).

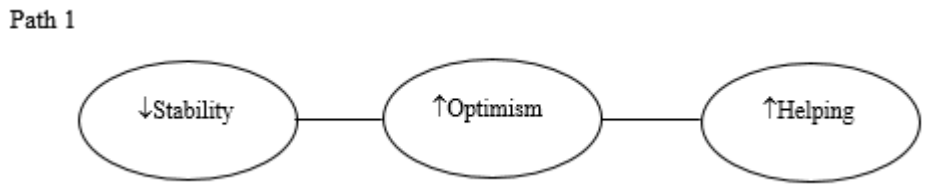
Only one out of the 15 studies (12) stated that a power calculation had been performed and was sufficient enough for the study design and analyses. With regard to statistical analyses, five studies (1, 2, 4, 11, 14) used planned and advanced analyses. Specifically, mediation analysis was used to predict the relationship between attributions and helping behaviour as well as the mediating role of emotions and/or carer's optimism for change. Seven studies used planned correlational analyses to explore key components of Weiner's model and/or regression analysis to determine which of these components were predictive of helping behaviour (3, 5, 6, 7, 8, 12, 13). Studies that carried out correlational analysis were unable to explore the mediating role of emotions or optimism for change, which are a key component of the model. Any relationships found do not fully evidence the applicability of the model. Three studies (9, 10, 15) examined any link between variables, rather than those specifically outlined in the model. This resulted in a broad correlational matrix and an overall poorer quality of study.

Eleven studies were appropriate in how they reported their conclusions. Five studies (2, 5, 7, 8, 11) provided limited reflections on their conclusions, for example taking into account smaller sample size and methodological weaknesses in their findings. Sanderson et al. (2007) state that highlighting the limitations of a study can help the reader to interpret the study findings and contribute to transparency in research. No studies declared any conflicts of interest.

Key findings

The key findings related to each of the three pathways proposed in Weiner's model are presented in Table 1, and are discussed below.

Three pathways in Weiner's Attributional Model of Helping Behaviour (1985)



Of the seven studies that explored Path 1, two studies (6, 14) found full support for a relationship between stability, optimism for change and helping behaviour. One study found partial support for Path 1, specifically that higher optimism was linked with carers' helping behaviour, however there was no evidence of a role for stability. These results used

vignettes to elicit carer responses. Two studies (3, 15) demonstrated no link between optimism and helping behaviour, however these studies used real life events to elicit carer responses, suggesting that optimism for change may be associated with helping behaviour in studies that use a vignette-based method only. One study (12) found that higher stability was weakly correlated with lower optimism for change and another study (13) found that higher stability led to carers engaging in more helping behaviour, both of which are contrary to Path 1 of Weiner's model.

Path 2

With regard to Path 2, two studies (6, 11) demonstrated that lower control led to an increase in helping behaviour, mediated by sympathy, which is consistent with Weiner's model. Three studies (4, 5, 8) found only partial support for Path 2, in that sympathy led to helping behaviour, however sympathy was not found to be a mediating variable between control and helping behaviour. One study did not find a link between control and sympathy (7). However, one study (15) did demonstrate a link between control and sympathy, but sympathy did not increase the likelihood of carer's engaging in helping behaviour. An inverse relationship was found in one study (9), whereby higher control was linked to positive emotions, which is inconsistent with Path 2 of the model.

Path 3

The results with regard to Path 3 were varied. Four studies (1, 2, 4, 6) provided support for Path 3, in that higher control and negative emotions were associated with lower helping behaviour. Contrary to this, four studies (5, 10, 14) found that control was not significantly correlated with helping behaviour. One study (13) found that control did lead to less positive emotions and more negative emotions, which is consistent with Path 3, however, negative emotions were not associated with carer's reduced willingness to help. Two studies (8, 11) found that high control led to a decrease in helping behaviour which is again consistent with Path 3, however there was no evidence of a role for emotions. Control was

also found to be a significant predictor of helping behaviour in one study (7), however, this study did not use a traditional measure of helping behaviour and alternatively measured carer's satisfaction with the intervention provided, which makes generalisation of their findings impossible.

In addition, one study (3) found that, contrary to Path 3, carers who perceived the person to have low control, showed higher negative emotions. Another study demonstrated that higher control and negative emotions leads to an increase in carer helping behaviour, which is also inconsistent with Path 3. These studies (3, 10) should be interpreted with caution as the ERCBS was adopted to measure emotions which involved collapsing depression and anger, two very different emotional states under one heading. Study 10 also trialled a new measure of helping behaviour with limited information provided about the reliability and validity of this measure (RCB).

DISCUSSION

The aim of this systematic review was to update the evidence base regarding Weiner's model, in particular whether the three pathways in this model are beneficial in explaining helping behaviours in paid and family carers looking after an adult or child with an ID and behaviours that challenge, within a home environment. None of the studies included in this review provided unequivocal support for Weiner's model. Studies found only weak support for a link between attributions and helping behaviour. Emotions were found to be associated with helping behaviour, however evidence that emotions act as a mediating variable were inconclusive. There was evidence of an association between carer's optimism that the behaviour will change and the likelihood of offering help to a person, however optimism for change was not measured across studies. These results were specific only to studies that used a written vignette-based method.

Possible reasons for the inconsistent study findings have been highlighted in the previous review (Willner & Smith, 2008) and have been expanded upon with the present review. Firstly, studies are heavily reliant on vignette-based methods to represent behaviours that challenge. Studies that have used real life events to elicit carer responses have the weakest support for Weiner's model, but stronger negative reactions are reported in those studies. This is thought to be because vignettes, unlike situations of real life behaviours that challenge, represent an abstract event which does not necessarily hold any personal significance to the carer and therefore may be more likely to bias how carers' respond (Willner & Smith, 2008b). Jahoda and Wanless (2005) propose that paid carer attributions

can be based upon the existing knowledge, and relationship history, of the person being cared for. This is known as the 'interpersonal context'. As a consequence of this, it is likely that carers will make a different decision as to whether or not to help a person depending on the method in which their responses are elicited. Secondly, Weiner's model was originally only intended for explaining low frequency behaviour (using the example of a person's willingness to help someone who had fallen in the street), and not "*behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others …"* (Royal College of Psychiatry, 2007 page 13). This model may be too simplistic for understanding how carers respond to behaviours that challenge. In addition, as behaviours that challenge can be frequent and reoccurring, it may be that carers are not responding to a single behavioural incident as proposed in Weiner's model. As such, carers may instead already hold a number of attributions and emotional reactions towards the behaviours that challenge displayed (Sharrock et al., 1990; Bailey et al., 2006).

Not all studies that have explored Weiner's model have differentiated between key attributional constructs, such as responsibility and controllability. This is a limitation of the studies in this area. It weakens the reliability and validity of its measurement and prevents judgments being made with regard to the utility of Weiner's model. Similarly, not all studies use the same definition for helping behaviour (e.g. a person's willingness to help or exert extra effort), with some studies instead measuring paid and family carers' practical responses to difficult to manage behaviour. This may be due to the potential for socially desirable responding, given the already helping nature of their caring role or that the current evidence base for managing behaviours that challenge is based on behavioural principles (e.g. that behaviour that challenge are positively or negatively reinforced by family or paid carers' responses). It can be argued that if a paid or family carer attributes the person's behaviour to something external, then this generates sympathy, which leads on to a behavioural response that may seem helpful in reducing the behaviours that challenge in the short-term, however, will act to strengthen the behaviour of both the carer and the person with an ID in the longer term (Allen, 1999). This is a further limitation and also impacts on the judgements that can be made with regard to the utility of Weiner's model within an ID context. Recent research by Ziljman, Embregts, Bosman and Willems (2012) have suggested that studies should focus on interactional style, rather than helping behaviour. Specifically, whether carer's interactions (e.g. friendly, neutral or controlling) can influence the development and maintenance of behaviours that challenge. Ziljman et al. (2012) found a link between carer attributions, emotions and interactional style, arguing that within communication research most people react to how things are said, rather than

what is said. As such, it would appear that future studies would benefit from exploring carers' interactional style at times of difficult to manage behaviour, alongside carers' experience of helping behaviour, as well as the presence or absence of this helpful behaviour.

It is important to highlight that the factors that influence carers' practical responses or helping behaviour will differ between paid and family carers. This should be considered when interpreting the findings of this review. Firstly, it can be argued that family carers will often have 24 hour caring responsibilities, unlike paid carers who are employed, undertake shift working and are more likely to have peer and organisational support available at times of difficult to manage behaviour (Allen, 1999). Secondly, the relationship with the person cared for will differ between both types of carers. Family carers may be the only person that has a continuous relationship with their relative throughout childhood and into adulthood and therefore, this enduring caring commitment may have a significant impact on their helping behaviour and behavioural responses to difficult to manage behaviour. Thirdly, some studies have suggested that external attributions (e.g. beliefs that the behaviour is out with the person with an ID's control) are more commonly held by family carers (Qureshi, 1994; Chavira et al., 2000). This is also consistent with studies that have involved other carer groups (e.g. family carers looking after a relative with dementia). It has been argued that external attributions may serve an important role in helping family carers adjust to the behaviours that challenge and allow them to continue in their caring role (Qureshi, 1990; Allen, 1999).

Willner and Smith's (2008) review found a number of theoretical and methodological difficulties with regards to the utility of Weiner's model. The current review improved on Willner and Smith's (2008) review by including a systematic literature search and an assessment of study quality. Despite this, this review found that the heterogeneity of the constructs explored, the sample characteristics and the variability in study quality contribute further to these inconsistent findings. As a consequence of this, limited conclusions can be made with regard to understanding carers' helping behaviour, or their responses to behaviours that challenge. Future research would benefit from exploring other theories or models to understand carers' behaviour (Hastings, 2002; Ajzen, 1991). Future research would benefit from using qualitative methodology initially, to give carers the opportunity to describe their lived experience and views of difficult to manage behaviour in detail. Hypotheses developed from this could then be later explored using quantitative methodology. Being a carer is recognised as an enduring caregiving commitment with considerable challenges (Wanless & Jahoda, 2002) and as such, the interpersonal

relationship carers' have with the person with an ID cannot be excluded, as this will potentially influence their responses to behaviours that challenge. Considering this further in the context of family carers who are looking after a relative with an ID and behaviours that challenge would be of equal importance given that this review found only two studies that explored family carer's cognitive and emotional responses to behaviours that challenge. This is surprising as family carers are a population who also provide a significant amount of care and support to children and adults with an ID, but are not well represented in the current literature.

Strengths and limitations

With regard to limitations of the present review, unpublished papers or papers that did not investigate Weiner's model were excluded, therefore important information could have been missed. This review only included articles published in the English language, therefore other appropriate studies may have been missed. No standard quality tool has been devised for observational studies, therefore the validity of this review could be raised. However, a strength of this review is that it included a systematic search and an assessment of study quality. The scope of this review was also purposely widened to include studies that involved family carers in addition to paid carers. It is acknowledged that the heterogeneity of the population is a limitation which reduces the generalisability of this reviews findings, however, a strength is that it does include an important population that have previously been overlooked in the literature.

Conclusion

The majority of studies in this review were 'adequately addressed' to 'well addressed' in relation to the study quality and spanned over two decades of research. Emotions were found to be associated with helping behaviour, however evidence that emotions acted as a mediating variable were inconclusive. There was evidence of an association between carer's optimism that the behaviour will change and the likelihood of offering help to a person, however optimism for change was not measured across studies. These results were specific only to studies that used a written vignette-based method. As a result, whilst some components of Weiner's Attributional Model of Helping Behaviour (1985) may help to explain carers' willingness to help a child or adult with an ID and behaviours that challenge, the largely inconsistent findings, methodological difficulties, variable study quality and limitations with the model, mean that no firm conclusions can be made with regard to its utility in real life caring situations. Therefore, the exploration of alternative theories or

models are essential to help better understand the factors that influence how carers' respond to behaviours that challenge. As part of this, future research could explore carers' responses qualitatively taking into account the history of their relationship with the person with an ID, as well as the interplay between the carers' cognitive and emotional responses at times of behaviours that challenge.

CONFLICT OF INTEREST DECLARATION

This review was conducted as part of the researcher's Doctorate in Clinical Psychology at the University of Edinburgh. Fees paid for by NHS Education for Scotland.

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The qualitative experience of family carers looking after an adult with an intellectual disability and behaviours that challenge

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ABSTRACT FOR EMPIRICAL PROJECT

Background: Previous research exploring factors that influence carers' responses to behaviours that challenge have primarily focused on paid carers within intellectual disability (ID) settings, using a quantitative method. There is a lack of research exploring family carers' experiences of looking after and responding to a relative with behaviours that challenge, particularly when the relative is an adult.

Research question: The present study aims to qualitatively explore the experiences of family carers who look after their adult relative and the factors that influence their responses to behaviours that challenge, using Weiner's Attributional Model of Helping Behaviour (1985) as a framework. This study also aims to explore these factors in the context of the interpersonal relationship family carers have with their relative.

Method: Seven semi-structured interviews were conducted with nine participants to understand their caring experience. Interviews were analysed using a hybrid approach to Interpretive Phenomenological Analysis.

Results: Five subordinate themes emerged from the interviews; 'searching for the reason', 'negative emotions and behaviours that challenge', 'tag-team approach – stronger together', 'limited support' and 'impact of caring'. Included in this were seven subthemes.

Conclusion: Participant's attributions and emotional responses to difficult to manage behaviour are complex and conflicting. Positive aspects of the interpersonal relationship with their relative mean that participants continue to care for and support their adult relative, regardless of their attributions and emotions at times of difficult to manage behaviour. Multiple other factors were found to influence participant's responses to behaviours that challenge. These factors are discussed in relation to existing findings. Clinical implications and areas for future research are suggested.

INTRODUCTION

Family carers provide a significant amount of care and support to children and adults with an intellectual disability (also known as learning disability) and behaviours that challenge, with recent statistics from the Scottish Consortium for Learning Disability (SCLD; Scottish Government, 2015) estimating that around 759,000 family members provide unpaid care to one or more relatives with an ID. This number may in fact be greater as often people providing unpaid care do not self-identify as a 'carer', as they see their relationship (e.g. as a parent) as one with caring activities integral to its role (Carduff et al., 2014). Caring for a relative can be described as a life-long caring commitment. Some family carers continue to have their relative reside in the family home throughout their adulthood (Seltzer et al., 2001; Hill & Rose, 2009). For many family carers, looking after and supporting an adult relative with an ID can be a positive experience (Griffith & Hastings, 2014, Hastings, Allen, McDermott & Still ,2002), however, this role can also lead to increased stress and mental health problems (Emerson, 2003), particularly when associated with difficult to manage behaviour. Heller et al. (1997) interviewed family carers, of whom, half reported their adult relative resided in a residential placement whilst the remainder continued to live in the family home. Heller et al. (1997) found higher carer stress and burden for family carers who cared for their adult relative within the family home. Despite the significant impact of behaviours that challenge on family carers, little is still known about the lived experience of those looking after their adult relative with behaviours that challenge.

Behaviours that challenge are often conceptualised as an interaction between the person and their environment, and as such are largely socially constructed (NICE, 2015; Dosen et al., 2010). Carers arguably form a large part of a person's environment, and as such, how carers' respond to behaviours that challenge will likely influence the development and maintenance of such behaviour (Hastings & Remington, 1994). The majority of evidence for this comes from work with paid carers (Willner & Smith, 2008; Allen, 1999). The lack of research relating to family carers is surprising, particularly for those caring for an adult relative. Understanding family caregiving situations is of paramount importance, not only because of the potential impact on the wellbeing of both family carers and their relative, but because family carers have a significant role in the management of behaviours that challenge.

The current evidence base for effective management of behaviours that challenge is based on behavioural principles, with increasing evidence for the use of applied behavioural analysis (ABA) (Grey & Hastings, 2005). As a result, family carers are often asked by

services to alter the way they communicate or respond to their relative's behaviour, however, this is likely to be a more complex task (Wodehouse & McGill, 2009). For family carers, they are not only asked to implement these interventions for their loved ones, which may be difficult in itself, but are doing so at times of considerable stress (Allen, 1999). In a qualitative study involving families of children with an ID, many parents viewed the behavioural intervention proposed to them as confusing. Some disagreed with the intervention or found it difficult to put it in to practice in real life. Interestingly, some parents viewed the intervention as 'at odds' with their own beliefs about the function of the behaviour displayed by their relative (Wodehouse & McGill, 2009).

Research involving carers have demonstrated that beliefs about behaviour (referred to in the literature as attributions) can influence an individual's response to behaviours that challenge (Armstrong & Dagnan, 2011; Willner & Smith, 2008). Specifically, a substantial amount of research has focused on Weiner's Attributional Model of Helping Behaviour (1985), which proposes that carer attributions about a difficult behaviour can result in emotions which, in turn, determines how carers' respond to the person. For example, if a carer holds the belief that the person with an ID is doing something to deliberately cause harm to others, the carers will be more likely to experience anger and will be less likely to offer help. Similarly, if the carer holds the belief that the behaviour is due to the person's condition or support needs they will be more likely to experience sympathy and to offer help. Although Weiner's model makes sense intuitively, studies that have explored the applicability of this model have been largely inconsistent in their findings. Two family carer studies investigated Weiner's model. Armstrong and Dagnan (2011) conducted a study with parents of young children with an ID and elicited their responses to difficult to manage behaviour using vignettes. Their study found evidence for a link between responsibility (linked in the literature to controllability) and increased punishing behaviour, mediated by feelings of anger, which is consistent with Weiner's model. Chavira, Lopez, Blacher & Shapiro (2000) similarly interviewed parents about real-life situations of behaviours that challenge. They found that the majority of the parents did not view their child as responsible for the behaviour. However, for the proportion of parents in their study who did, partial support was found for a link between attributions and punishing behaviour. Attributions were also found to be linked to a range of negative emotions, but unlike Armstrong and Dagnan (2011) study, emotions were not found to be a mediating variable as proposed by Weiner's model. Both studies provide inconsistent findings with regard to the utility of Weiner's model to real-life family caregiving situations. However, both studies did highlight that the relationship between difficult to manage behaviour and family carers attributions and emotional reactions may be more complex.

Previous carer research (Willner & Smith, 2008) has found a number of theoretical and methodological limitations with Weiner's model and with the studies that have explored this model. One criticism is the reliance on theoretical rather than real-life situations when eliciting carer responses to behaviours that challenge (Wanless & Jahoda, 2002; Bailey, Hare, Hatton & Limb, 2006). Wanless and Jahoda (2002) reported that vignettes can offer good stimulus control and can be a useful research tool, however they represent an abstract event that does not have personal significance for the carer, and therefore fails to capture the full range of cognitive and emotional reactions experienced by the carer. Jahoda and Wanless (2005) compared paid carers' responses to both real life situations of behaviours that challenge and to hypothetical written vignettes. They found that carers' experienced stronger emotional reactions towards real life incidents of behaviours that challenge. Jahoda and Wanless (2005) concluded that carers may not just be responding to the latest episode of behaviours that challenge, but also to the person. This suggests that carers' cognitive and emotional responses to behaviours that challenge may be influenced by the context of the interpersonal relationship they share with the person they care for (Jahoda & Wanless, 2005). This is of particular importance for family carers, as this interpersonal relationship can be complex, enduring and arguably continually evolving over the course of a life time. Exploring family carers' experiences in the context of the relationship they share with their adult relative may be difficult to capture using quantitative methods (Amaresha & Venkatasubramanian, 2012). Restricting family carers' experiences to a number of pre-defined variables, such as in Weiner's model, only serves to limit the understanding of factors and underlying processes that may influence these factors. Social constructionist methods, such as Interpretive Phenomenological Analysis (IPA) provides a means of exploring lived experiences and views which are personally significant (Smith, Flowers & Larkin, 2009) and as such provide a richer, more detailed insight into the experiences of family carers who respond to behaviours that challenge.

Aim

This study aims to address the gaps in the literature by using semi-structured interviews for data collection and a multi-modal approach to data analysis. This study will 1) explore family carers' attributions and emotional reactions to behaviour that challenge, using Weiner's Attributional Model of Helping Behaviour (1985) as a framework and 2) explore family carer's lived experience of looking after their adult relative with an ID and behaviours that challenge within the home environment.

METHOD

Ethics

The University of Edinburgh School of Health in Social Science Ethics Committee granted ethical approval on the 9th of July 2019 (reference no. CLIN659). See Appendix D and E.

Participants and recruitment procedure

All participants lived with an adult relative in the United Kingdom (UK). Participants were included if they perceived their relative to have both an ID and behaviours that challenge. The Royal College of Psychiatry (2007) definition of behaviours that challenge was utilised, meaning that their adult relatives must display aggressive behaviour, self-injurious or stereotypical behaviour that is of an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of their relative or those around them. Due to the high co-morbidity in ID, additional diagnoses did not lead to exclusion. Participants were not included if their relative 1) did not reside with them in the family home 2) were aged 16 or under or 3) were currently receiving inpatient treatment. The sample was opportunistic and comprised seven semi-structured interviews with the first nine participants who were willing and eligible to participate in the interview process. Twenty-six potential participants contacted the researcher for an information pack, of which 12 did not contact the researcher again. A further three were not eligible to participate as they did not perceive their relative to display behaviours that were challenging and two did not currently reside with their relative. Recommendations from other IPA studies suggest that a sample size between six and 12 participants is typically sufficient for understanding common perceptions and experiences among a homogenous group (Smith et al., 2009).

Six of the participants were female, three were male. Five participants were interviewed individually and four, Eric and Brenda and George and Agnes, were interviewed as a couple. Both couples felt that this would lead to a better account of their caring experience. All participants were married and a parent to their adult relative. The mean age of participants was 57 years (range = 40 to 84 years). Six participants stated that they had part-time paid employment in addition to their caring role and three were retired. With regards to the participant's adult relative, four were male and three were female, with a mean age of 28.9 years (range = 18 to 53 years). Participants stated that they relied predominately on immediate family for support, but they did also receive respite or additional support from external care providers. The relatives of five participants were receiving support from

Social Work Services or their local Community Learning Disability Team, but only one family were receiving support specifically for managing behaviours that challenge. The demographic characteristics of the participants included in this study are presented in Table 1.

Table 1: Demographic information of participants and their relatives with an ID ***all names have been changed to ensure confidentiality***

Participant	Gender of participant	Age of participant	Relationship to relative	Additional supports	Age of relative	Gender of relative	Diagnoses in addition to ID	Type of CB
Diane	F	50 - 60	Mother	Care Provider	20 - 30	M	ASD	VA
Patricia	F	50 - 60	Mother	Social Services CLDT Respite	20 - 30	F	PWS ASD	VA PA
Eric* Brenda*	M F	40 - 50 40 - 50	Father Mother	Care Provider Social Services	20 - 30	M	ASD ADHD	VA STB
George* Agnes*	M F	80 – 90 80 - 90	Father Mother	Day Centre CLDT	50 - 60	F	Bipolar Disorder Epilepsy	VA PA
Jackie	F	50 – 60	Mother	Care Provider College CLDT	20 - 30	M	ASD PWS	VA STB
Nicola	F	40 - 50	Mother	Care Provider Social Services	20 - 30	F	None	VA PA
Graham	M	60 - 70	Father	Care Provider Social Services	20 - 30	M	Down Syndrome ASD	VA STB

NB: M: Male; F: Female; ID: Intellectual disability; PWS: Prader-Willi Syndrome; ASD: Autism Spectrum Disorder; ADHD: Attention-Deficit Hyperactivity Disorder; CMHT: Community Mental Health Team; CLDT: Community Learning Disability Team; VA: Verbal aggression; PA: Physical aggression; STB: Stereotypical behaviour; *: Denotes that the person was interviewed with their spouses present.

Participants were recruited through social media, namely *Twitte*r and *Facebook*. Those who contacted the researcher directly to express an interest were sent an information pack via email or through the post. Each information pack contained a Participant Information Sheet (Appendix F) and Consent Form (Appendix G). Participants, if they were interested in taking part, were asked to contact the researcher to arrange a mutually convenient date and time to meet. Prior to collecting any data, the researcher went through the information sheet with participants, reiterating the purpose of the study, their involvement and subsequent right to withdraw from the study at any time, without requiring to provide a reason. If there were no concerns from participants, written consent was obtained. The procedure of how interviews were conducted was diverse (i.e. face-to-face, telephone, Skype). This was to allow family carers to still participate in the study even if face-to-face contact was not feasible due to their caring commitments. To capture a range of caring experiences, recruitment was widened to include the whole of the UK. This meant that telephone and Skype methods were also considered to be the most appropriate. The demographics of family carers and their relatives was diverse, particularly in terms of the topography of the difficult to manage behaviour, the adult relatives' co-morbid diagnoses as well as the age ranges of the family carers and their relative. Whilst this is a limitation, it is a sample that is thought to be clinically relevant and mirrors the complexities of families seeking support for their adult relative with behaviours that challenge.

Interviews

Participants were asked to complete a brief demographic questionnaire (see Appendix H). This included information regarding age, gender, marital status, relationship to their relative with an ID, length of time caring and current supports which are in place. Information was also collected regarding each participant's adult relative's gender, age and diagnoses. Participants were then asked to provide a first-person account of their caring experience. Interviews took place over the telephone or via Skype, with the exception of one interview, which was conducted at a local carers centre. Telephone and Skype have been used successfully in past research (Hanna, 2012) and have been evaluated as a suitable research tool, with guidance for its usage produced (King & Horrocks, 2010). Following interview, participants were offered an optional follow-up phone call, given the nature of the topic area. Two participants opted for this. One participant disclosed a possible Adult Support and Protection concern leading to information being passed on to their local Social Work Service, following local authority adult support and protection safeguarding guidance.

The aim of the interview was to elicit family carer's specific views and experiences of looking after their relative with an ID and behaviours that challenge. A semi-structured interview schedule was utilised flexibly to guide the interview process (see Appendix I). The development of the interview schedule was constructed with the research question in mind and was based on existing literature relating to the impact of caring, available supports and family wellbeing, as well as research regarding Weiner's Attributional Model of Helping Behaviour (1985). The interview comprised open-ended questions, thus allowing participants to talk freely. Minor prompts by the researcher were only included if required to refocus the conversation or to encourage the participant to elaborate further. Interviews varied in length between 49 and 89 minutes, with a combined interview time of 7 hours and 34 minutes. Interviews were recorded using two digital recording devices and subsequently transcribed verbatim by the researcher. All identifiable or contextual information was removed at transcription and pseudonyms were used for each participant.

Interpretative Phenomenological Analysis

Semi-structured interviews were analysed using Interpretative Phenomenological Analysis (IPA). This is a qualitative method of analysis that aims to explore systematically and in detail the meaning, in this case of family carer's experience of looking after their relative with behaviours that challenge. The process of IPA helps aid the researcher in understanding how participants make sense of their lived-experience and to ascertain key themes across different accounts (Smith et al., 2009). The data was also analysed flexibly using a multi-modal approach. This involved focusing on deductive approaches to develop themes that were based upon the existing literature (e.g. Weiner's model) and inductive approaches to explore family carers' experiences.

The process of data analyses followed the steps proposed by Smith et al. (2009): (1) reading and re-reading; (2) initial noting; (3) clustering similar themes to form sub-ordinate themes with supporting extracts from the transcription; (4) searching for connections across sub-ordinate themes; (5) moving to the next transcription; and (6) looking for patterns across transcriptions to provide an over-arching structure and a collective reflection of the participant's experiences. IPA acknowledges the position and influence of the researcher, in this case the first researcher is a Trainee Clinical Psychologist with an interest in systemic approaches to working with adults with an ID and behaviours that challenge. IPA research also acknowledges that a natural bias can develop as a result of one's own experiences (Smith et al., 2009). The researcher mitigated this by utilising academic and

clinical supervision regularly to reflect on, at times, unexpected emotional reactions to participant's narratives and how this guides the interpretation. Instead of viewing this as a research bias, these reflections were considered an important part of the process throughout the interviewing, transcription and analyses of the data. This allowed for the development of a dialogue between the data, the researcher and their psychological knowledge, thus resulting in an interpretative and in-depth account of the data and the relationships between the themes identified. The final written draft of this study was read alongside the transcripts to ensure a valid account was provided.

RESULTS

Five themes and seven subthemes emerged from the analysis. Although these themes are separate, overlap between some were apparent, particularly in relation to the range of attributions and emotions experienced by the participants in response to behaviours that challenge. All participants had experience of behaviours that challenge that were severe and enduring in nature, and for one participant this had resulted in police involvement. Despite the level of behaviours that challenge that were displayed, all participants were very keen to demonstrate the many positives aspects of their caring role, and at times it was clear that they found it difficult to be seen to talk negatively about their relative. Many used humour, particularly in their response to questions that were emotive, and on occasion it appeared that some participants were keen to minimise the extent of their experience. For some, reflecting on the reality of their experience was understandably uncomfortable, however, the researcher spoke with each participant prior to the interview to help build a level of trust so that they felt more able to open up about their familial relationship and experience of behaviours that challenge. Extracts that encapsulate the essence of each of the themes in Table 2 are presented.

Table 2: Summary of subordinate themes and sub-themes

Subordinate themes	**Sub-themes**
1. Searching for the reason	1.1 They can't stop it – biological factors
	1.2 They know what they're doing
	1.3 1 It's our fault
2. Negative emotions and behaviours that challenge	
3. Tag team approach – 'stronger together'	
4. Limited support	4.1Why must we fight?
	4.2 One size does not fit all
5. Impact of caring	5.1 The long-term personal impact
	5.2 Fears about the future – 'the dilemma'

Theme 1 - Searching for the reason

This deductive, subordinate theme explores participants understanding as to the reasons why they believe that their relative behaves in certain ways. Contrary to Weiner's model, participants offered multiple attributions which were ever-changing depending on the situation and their own individual experiences, and were often conflicted in their quest to accept and understand their relative's behaviour. A number of these attributions are considered through the following sub-themes:

1.1 They can't stop it – biological factors

When discussing their relative, participants explained their relative's behaviour in terms of having a biological or physical cause, giving examples such as the impact of hormones around puberty, the effect of medication and their life-long disabilities. When this biological explanation was given, participants were very clear that they believed their relative was not in any way in control of their behaviour, that it was not a choice they were making. Eric talked about his son's prescribed medication becoming ineffective in the evening, resulting in an increase in the likelihood of a behavioural incident occurring:

> *The impulsiveness comes across him and we cannae stop him. He gets the idea and he has to act on it. As it tends to be in the evening when his medication is tailing off, so it maybe could be something like that? He can't stop it. –* ***Eric***

Similarly, Diane provided a number of biological explanations in her pursuit of understanding:

> *I was thinking, why is he so badly behaved? Because he was 16 at the time maybe? [making reference to puberty]. It was a long time to go through wondering why he was so badly behaved, but when we got the diagnosis [of an ID and ASD] it all started to make sense for us. –* ***Diane***

For Diane, her son being given a diagnosis was an important step as it appeared to have brought about a sense of clarity to her understanding of her son's behaviour. This was something Diane tried to remember during times of difficult to manage behaviour. For Agnes and George, having reassurance from a medical professional that their daughter did not have control over behaviours that challenge due to her diagnoses was helpful for them:

> *What the psychiatrist explained quite a few years ago now, was that X knows what she is doing but she can't stop herself doing it. That's why she comes and says sorry afterward. –* ***Agnes***

> *So you know it's just part of her learning disability and that's it. –* ***George***

This also appeared to evoke fewer negative beliefs about the behaviour for this couple as highlighted in Agnes' sentence "*That's why she comes and says sorry afterward*".
By viewing this apology as their daughter being remorseful for the behaviour, appears to help Agnes and George to understand and accept this difficult situation by separating the behaviour from the person, i.e. that the behaviour is not intrinsic to their daughter.

1.2 They know what they're doing

Although participants talked about a biological cause being the main reason for behaviours that challenge, Eric talked about his belief that his son can act, at times, in a way towards him and his family that is more targeted, deliberate and under his control:

> *He is happy with his peers, he joins in and laughs…but in the house he is deliberately doing things to wind his brother up, hitting him and stuff, and he kens [knows] it's not okay. –* ***Eric***

Jackie similarly described that her son can, and does, behave differently during a behavioural incident when with paid carers as opposed to someone he has a close relationship with, such as a family member. She believes that he can choose how he responds to an instruction, indicating that he has some control over this:

> *He is able to moderate his behaviour when he is out and about so if he goes out by himself he doesn't have a meltdown in the shop if they haven't got what he wants. He will actually think about choosing something different or he reacts in such a way that his carers help him and give him suggestions which is good. When he is with someone he knows, like me, he is more likely to have a meltdown. –* ***Jackie***

George talked about a behavioural incident where he felt that his daughter was altering her behaviour in response to him reprimanding her, but that this was not something she would do for her mother:

> *She thinks her mum is a soft touch… At times, I can lose the place with her and you know, just tell her off and she just settles there and then. She'll listen to me, whereas she'll no [not] her mum. –* ***George***

These excerpts appear contradictory to the previous sub-theme, in that, at least on some occasions participants do view their relative's behaviour as deliberate and under their relative's control. This is not as straightforward as proposed in Weiner's model, as participants in this study tended to hold multiple and conflicting attributions which alternates depending on the incident and the context in which it takes place.

1.3 It's our fault

Over time, in participants' continual pursuit of understanding their relative's behaviour, their reflections can often turn inwards, leading them to consider whether their own actions and the way they have parented may be the reason for the behaviour occurring and being maintained:

> *After a while we kinda blamed ourselves really. I don't know... we blamed ourselves because we thought we were doing the right thing, but we must be doing something wrong, you know? And just questioning our parenting skills actually.* – ***Diane***

Eric talked about giving in to his son's repetitive demands, just for a 'quiet life'. Both he and his wife were clear that this resulted in preventing a behavioural incident occurring in that moment, but made it harder for them to reinstate consistent boundaries for their son in the future. As Eric and his wife were very much aware of this, it perpetuated their feelings of self-blame:

> *We're running out of steam and you hear him going into the kitchen and you're like "ugh, just go on" it's not worth the fight (laughs) it is hard to keep the discipline up the full…24 hours of the day.* – ***Eric***

Jackie spoke about feeling that she too was in some way to blame for the behaviour displayed by her son. She attributed this to feeling isolated in her caring role and not having other parents or children to compare her experience of parenting to:

> *We don't have a measure of another child so it's quite hard…so you don't know if there is another parent down the road being screamed at by their 21 year old because they were asked to put their coat on…so is a conversation going on like that in households across the country? Does he match up to other children... or is it something I'm doing?* ***– Jackie***

Brenda was very much resigned to the idea that she was inherently to blame not only for the behaviours that challenge, but also for her son's lack of happiness and wellbeing prior to him receiving additional support at home:

We would try and bring him to clubs, but it was a fight and we would just give in a lot of the time. But now…and he was overweight. And now you see him, now he is fit as a fiddle, looks amazing, out 3 or 4 times a week, happy, why would you not look at that and say "I must have been doing something wrong…?! To me that's a no brainer. – ***Brenda***

This visible change of improvement in her son's presentation, served only to strengthen her feelings of self-blame. This statement from Brenda was particularly powerful in that she said this in such a matter of fact way and with conviction creating no space in which to even contemplate an alternative perspective.

Theme 2 - Negative emotions and behaviours that challenge

Another deductive subordinate theme relating to Weiner's model is the participants' emotional reaction to behaviours that challenge. Participants reported experiencing a range of predominately negative emotions during or immediately following a behavioural incident, linked to their attributions. Their emotions appeared to be either internalised (e.g. feeling anger about the situation) or externalised (e.g. feeling anger towards perceived judgement from others) during an incident:

I still get really angry, but I have to walk away. You've really got to because if you are angry and trying to deal with it [the behaviour] then it would just get worse…and X would get even more angry and it wouldn't help him. - ***Eric***

Eric talked about the need to remove himself temporarily in order to avoid overreacting emotionally to the behaviour displayed by his son. Removing himself is Eric's primary way of coping, providing a safe space in which to calm down and ultimately resulting in de-escalation of the situation for both Eric and his son. Similarly, Jackie talked about having to do the same to protect her own wellbeing and that of her son:

…Either you remove yourself from a situation or you get fed up with it and you don't help…so…it can be quite challenging. We ehm have taught people that you remove you from X. – ***Jackie***

Despite Nicola also understanding the importance of removing herself to de-escalate the situation, she was clear that this was not an easy thing for her to do emotionally. This highlights that what works for one person does not necessarily work for another. Nicola

finds it very difficult to make herself retreat from her loved one who is in distress. Her intuition, like that of several other participants, is to want to comfort and hold her daughter close, rather than move further away. This is where internal conflict arises for Nicola because she feels she must act in a way that is the opposite to how she would like to respond in order to de-escalate the situation and alleviate her daughter's distress:

> *Ehm…over the years I've tried to sort of still be there though but not too near causing her more stress. When you're in the situation where it's somebody you love and you know and you don't want them to be upset, you don't want them to be alone. –* ***Nicola***

Several participants also talked about struggling with the reactions of members of the public towards their child during a behavioural incident, and the negative emotions that this elicited for them. Weiner's model proposes that carers who hold the belief that their relative is not in control of their behaviour will experience sympathy towards their relative. For Diane, the emotion she described is not sympathy in the sense that she feels pity or sorrow towards her son or the difficult to manage behaviour, but rather anger and frustration, which she directs outwards towards those witnessing the incident and their perceived forming of negative opinions and judgements about her loved one, based on only a snapshot in time:

> *I don't want other people thinking he is a bad person. And that is my main thing now because I know he isn't a bad person…and he…society…is unfortunately quite cruel and I see people looking at him and obviously he is my child so I get really defensive…and quite annoyed really. It wouldn't be the first time that I've went up to somebody and said look…my child has disabilities and can't help the way he behaves. –* ***Diane***

<u>Theme 3 - Tag team approach – 'stronger together'</u>

Prior to the interviews, two participants contacted the researcher and expressed the importance to them of being interviewed with their spouse as they considered themselves to be two halves of one whole parenting team. This inductive, sub-ordinate theme demonstrates the central role of teamwork for these participants in their joint caring role. This is particularly interesting as this spousal relationship was not specifically asked about during the interview or a pre-requisite for participation in the study.

For Patricia, her and her husband both provide care and support for their daughter and try to take equal responsibility for being the one to make unpopular decisions and enforcing healthy boundaries with their daughter. When the situation becomes more challenging for either partner, they then retreat as a couple from the situation to gain some distance and to discuss their individual responses to the behaviours that challenge. By doing so, this serves to help the couple bring about a change in their negative reactions to the situation, thus ensuring that they maintain a balanced perspective and enabling them to continue to be a cohesive caring unit for their daughter:

> *We tend to try and be sort of good cop, bad cop between myself and my husband (laughs)… I tend to be bad cop and my husband tends to be the good cop but we can fluctuate, but it just depending on the circumstances ehm and also the stresses because sometimes when you are smack bang in the middle of it you can get embroiled into a situation and it just takes somebody else to come in and say "just hang on, just hang on" let's step outside or let's just, you know, talk about it together you know? I do tend to be a bit of a bad cop but (laughs).* – ***Patricia***

Diane also describes a reciprocal and alternating role between herself and her husband. She describes the importance of one partner stepping forward to provide all care, at times of stress for the other. This then allows time to retreat to regain strength and emotional resilience. This supportive team working approach not only offers and provides support to each other but also allows both partners to cope with their increased caring role at times of difficult to manage behaviour:

> *The good thing is that there is always one of us stronger than the other. I would have a good day and be able to cope and other days, maybe not so able and my husband would step in.* – **Diane**

Graham also spoke about the importance of not only the flexibility of team work, but the almost strategic nature of this "tag-team" between himself and his wife in caring for their son, and in particular when managing a behavioural incident:

> *I find generally concerted actions by both parents can be more attractive than, than instruction from one, so if he doesn't take it from me I can always pull mum into the ring and she can have a go (laughs). At this point he is more likely to go along with whichever parent is the least likely to be the nag (laughs).* – ***Graham***

4. Limited support

This inductive subordinate theme explored participant's experiences of statutory services. All participants relied extensively on informal family support for help to look after their relative with behaviours that challenge. Although this did allow them the advantage of providing care in their home environment within the context of the family, all participants, except one went on to explain that there is limited support available from statutory services, should this be required. Some participants described not feeling listened to when they were communicating a need for extra support and as such, on most occasions, described feeling as though they had no option but to become more vocal and assertive in their quest to achieve this. When support was eventually offered, many participants felt that this was inadequate as it was not in any way tailored to their relative's support needs. For some, these perceived battles led to further frustration, and at times, a ruptured relationship with services.

4.1 – Why must we fight?

Jackie described her continual battle with statutory services to obtain appropriate and necessary supports for her son. She felt angered at the extended process involving multiple different professionals and services. The most frustrating part of this for Jackie appears to be the fact that services were not recognising the need to be proactive. Her son's complex support needs will not improve over time and he will inevitably require access to these services in the future. For Jackie, her caring role would be made much easier if her son received timely, streamlined support when required:

> *He's got an open-ended ability for me to go back to Services if I ever needed it…mainly because I have that written in absolutely everything in hospitals…(laughs)…I'm a bit of a horrid parent to be honest (laughs) if you are going to discharge me you're doing it under my rules, not yours. Otherwise you have to get a referral done…and I'm not doing that. You know? I'm sorry my son has a life-long condition and therefore the chances are he will likely need your services again so don't make all that crap up about going to my GP who doesn't see my son and you expect them to waste their time writing a letter? No (laughs)…you know?* **- *Jackie***

Patricia also described not feeling listened to when communicating a need for extra support for her daughter. Patricia describes perceiving services to be working against her rather

than with her, particularly as she has good knowledge and understanding of her daughter and her support needs. There is a sense of frustration from Patricia that her perspective is not considered at all when services are making important and potentially life changing decisions about her daughter.

> *The social worker here, that she is now with…and these people that she was involved with [Community Learning Disability Team]…really dismissed everything that I was trying to say…I know my daughter…and everything that I've said is now coming happening but it's putting my daughter through all these unnecessary stresses that I tried to stop.* – ***Patricia***

Diane talked about receiving the right support eventually for her son she felt may have other diagnoses that could better explain his behaviour. Diane was left feeling let down and disappointed at the battles her son and her family had to endure and the length of time it took to receive help, something which could have been avoided:

> *We kinda didn't let it lie. We fought for his social worker and help for his behaviours. We've had to fight at every turn. I felt that the system had let us down*. ***- Diane***

4.2 One size does not fit all

Linked to the previous inductive sub-theme and the battle to access reasonable support for their relative, is the disparity between what participants are asking for and what is provided by statutory services. In most cases, this was due to difficulties by services in taking into account the ever shifting nature of behaviours that challenge. For example, Jackie talked about being offered strategies for coping with the behaviour displayed by her son, but these were often generic and therefore difficult to implement due to them failing to target the specific needs of her son. Jackie was frustrated as she viewed that services were unable to offer any new knowledge or a tailored intervention to help her to continue to be responsive to the difficult to manage behaviour:

> *We had quite a few episodes so I pushed hard for him to go through CAMHS and we…we did get some coping strategies for him. Obviously, we went and saw people …that it is, you know, what people find really hard was that, he didn't always have the same triggers so when we went to CAMHS and places for help it was very difficult. They can give you a coping strategy based on what we have told them*

happened last week, and then he has a meltdown about something completely different and you are like "well hold on, that's been like that for the last 6 months, why all of a sudden has that changed now! – ***Jackie***

George and his wife also talked about the support that was available not being flexible at the time that they required it. George and his wife, who are both elderly, were clear that they valued the time they spend with their daughter, however, were left with no support at a point when their daughter's behaviour was at its most difficult to manage. This was despite requesting immediate support. Given the absence of an alternative, they are left with no choice but to continue with the caring role regardless of the impact of this both emotionally and physically on their wellbeing. Being offered to plan respite far in advance does not benefit or support George, his wife or their daughter in any way, and perhaps a more flexible option for respite would improve their caring situation and prevent things reaching crisis point:

A couple of times we have said to the community nurse, you know, that X is getting out of hand and have been told there was no place to take her in [respite]. We are told it doesn't work that way and we would have to just wait. I told them that by the time a space came around anywhere, X would be out of the hypermania stage she is in so that's just no help to us. – ***George***

Brenda and Eric similarly talked about their son's support not being person-centred or tailored to either their or their son's preferences, due to the set-up of their local Social Work Department. They perceived that this meant that their son's options for the future are to continue to remain at home, which is not a long-term solution for them, or to reside on his own with support. The latter is a situation that Brenda, Eric and their son fear as this has the potential to impact on, not just their son's emotional wellbeing, but the difficult to manage behaviour:

It's unfortunate…we live in X Council. They don't quite support our idea or the idea of people living in groups, but for my son I think it helps. If he was on his own then I personally think it would be detrimental to his health and his behaviour, but they don't see it like that. – ***Brenda***

5. Impact of caring

5.1 Long term personal impact

The impact of the participants caring role is another important inductive subordinate theme. Despite participants communicating the many positive aspects of the relationship they have with their child and of their caring role, they also described the relentless and all-consuming nature of caring. For Eric and George, and their wives, this often resulted in physical and mental exhaustion. Their desire to continue to provide love and support for their child appears to be the driver which allows them to push through this exhaustion in order to continue caring:

> *You are knackered…you are trying all day to say, don't do this, don't do that. Our first social worker said we were like a pair of goalkeepers that just keep going (laughs). –* ***Eric***

> *Basically it just leaves us feeling pretty shattered and wanting to go to bed... we wouldn't have it any other way, we love him. –* ***George***

Patricia described engaging in a variety of avoidance behaviours, namely continually keeping busy and avoiding having any unaccounted for time in which she may ruminate and worry. It appears that if she were to have this time, she fears that she will no longer be able to cope with the reality of how difficult her caring role is:

> *There's a part of me that thinks if I do give too much time to dwell on things it'll come on, you know, I'll suddenly develop all these mental health problems (laughs)…so I want to avoid that (laughs) 'cause I know I hate taking medication because my mother took medication for all her life and I'm trying to avoid doing that in every possible way. So I think if I just keep myself busy, it's not going to happen to me (laughs). -* ***Patricia***

Similar to Patricia, Nicola also struggles with the prospect of having time outwith her caring role, and she acknowledges that she will anxiously plan ahead and actively prevent herself from having this time by taking on non-essential additional responsibility. For Nicola her worry that she will become unwell drives this apparent practical necessity to keep herself busy. Without this avoidance strategy, she also fears she would be unable to continue to cope with caring for her daughter:

> *What do I do when my kids go away? I decide I'm going to start working 9 hours a day (exaggerated tone) to put in the hours I don't do the rest of the year!... I've got to keep busy because I'm so used to be being busy…I don't…I don't…if I had too much time to think I might have a breakdown. So, probably if I just keep moving and doing things then I won't (laughs). –* ***Nicola***

As a result of caring for their child, many believed they had no option but to compromise or make sacrifices in their daily life. For the majority of the participants, they reported that these sacrifices mainly came with regard to giving up spending time as a couple, for the sake of caring for their child:

> *The last couple of years we almost do things separately. There is very few times…like we used to do a lot travelling about just the two selves together, like islands or stuff. Now, if you go somewhere, I would go somewhere else like last year. We do things separately to relax now. It's hard to find things to do together as we don't have the time together. Someone needs to look after X. –* ***Eric***

This sacrifice in the time they spend together is also true for Patricia and her husband who as a consequence of caring for their daughter with difficult to manage behaviour also have no alternative but to do things separately to recharge. Despite Patricia making light of this there was a definite sense of sadness for her at the loss of the opportunity to spend quality time as a couple:

> *You can't go out. You haven't got much of a life (laughs)…my husband and I never go out together. We have to do it between us. If one goes out, the other one has to stay at home with X. –* ***Patricia***

5.2 Fears about the future – 'the dilemma'

There is a prominent inductive subordinate theme for all participants around the future, in particular, worrying about who will care for their loved one when they are no longer able to. This is of particular concern due to the complexity of the care needs surrounding behaviours that challenge. Participants spoke about the uncertainty and apprehension of future service provision for their relative and their ability to cope. Diane was adamant that she could not contemplate her son living outwith the family home, even if this came at a cost to her personal life and her own mental health:

We want to care for him…we don't want him to go somewhere and if that means being anxious on a daily basis and having to deal with his behaviour then so be it…I love him. – ***Diane***

Graham described similar strongly held beliefs, but for him his opinion is that the love, protection and understanding that himself and his wife can provide their son during a behavioural incident could in no way be replicated by paid carers:

I would say the quality of support provided by family, like our own, which is fairly resourceful, is probably significantly better in terms of quality of life than the range of support services which could be provided even in an ideal world in a professional paid support service. Ehm...even if that was an individual one it would still be difficult to recruit the quality of staff that had the same level of empathy, understanding and care and love for our son when he is upset. – ***Graham***

Agnes views their caring situation differently. Agnes highlighted that both her and her husband are in their eighties, and that although a move would be difficult emotionally and practically, it would ultimately benefit their daughter in the future:

...I'd be happy if I could oversee her care somewhere else…so that I could explain everything [about their relative's behaviour] to the people looking after her. You know you've got in your mind that she's not going to like it but at some point we aren't going to be here…it would be better, better for me to, if we could oversee it…initially at least. – ***Agnes***

DISCUSSION

This study aimed to explore the experiences of nine family carers looking after their adult relative with an ID and behaviours that challenge, using Weiner's Model of Helping Behaviour (1985) as a framework. This study also aimed to explore these variables in the context of their interpersonal relationship and participant's lived experience of behaviours that challenge. All of the accounts were understandably personal to each participant and their caring experience, however several prominent themes were identified across the data. Each participant spoke about the nature of the relationship with their relative, the multiple and conflicting attributions, negative emotions at times of behaviours that challenge, the importance of having their partner for support, the limited support available from statutory

services to help care for their relative and the long-term impact of caring. It is important to highlight that all participants had experience of behaviours that challenge that were severe and enduring in nature. Despite the level of behaviours that were displayed, all participants were very keen to demonstrate the many positives qualities of their relative and their caring role, and at times it was clear that they found it difficult to be seen to talk negatively about their relative. For some, talking about the often negative reality of their caring experience was uncomfortable and some appeared to attempt to actively minimise conversations around this.

Components of Weiner's Attributional Model of Helping Behaviour (1985)

'Searching for the reason' and 'emotional reactions and behaviours that challenge' were themes identified using deductive analysis which incorporated components of Weiner's model. Across all accounts, participants were often mixed and conflicted in their attributions, offering multiple explanations in their quest to make sense of and understand the behaviour displayed by their relative. This study captured some of the complexity of attributions held by family carers. Participants did identify specific incidents where they believed their relative was in control of their behaviour, but some participants apportioned blame to themselves and their parenting abilities. However, on reflection, and with some distance, participants were able to conclude that this was generally not the case. For the main, participants believed that the most dominant attribution towards behaviours that challenge was that of a biological one (e.g. related to their relative's complex support needs) and ultimately not within their relative's control. This is somewhat consistent with Chavira et al's (2000) study which asked parents of children with an ID to recall incidents of behaviours that challenge. Their study found that the majority of parents did not attribute control or blame to their child for difficult to manage behaviour. However, this is not consistent with Armstrong and Dagnan (2011) who found that parents' rated their children as significantly more in control of and responsible for the behaviours that challenge. Armstrong and Dagnan's (2011) findings may be due to the use of vignettes to elicit carer responses, a method which has been widely used in paid carer studies relating to Weiner's model (Willner & Smith, 2008). It could also be argued that attributions of control are related to how a family carer feels in that moment of stress, but with time and distance their perspective changes, which is similar to previous studies in this area (Wanless & Jahoda 2002; Jadoda & Wanless, 2005). Linked to carer attributions, Weiner's model proposed two emotional reactions to behaviours that challenge; anger from those who attributed the behaviour to be under the person's control and sympathy from those who attributed the behaviour to be out with the person's control. Participants did not describe feeling a sense

of sympathy during difficult to manage behaviour. This is similar to Dagnan and Weston's (2006) paid carer study, however is inconsistent with McGuiness and Dagnan (2000) who found that sympathy was the biggest predictor of helping behaviour. Participants in the current study appeared to feel predominately angry, not at their own discomfort of the behavioural incident, but towards the perceived judgement of their child from members of the public. The multi-faceted nature of anger is not something that is captured in Weiner's model. However, regardless of participant's feelings of anger, this did not result in them engaging in unhelpful behaviour or a reduction in their willingness to help their relative. Participant's described having a strong desire to continue to support and protect their loved one during difficult to manage behaviour. This love and affection undoubtedly helps some participants through many of the difficulties of looking after their adult relative with behaviours that challenge (Griffith & Hastings, 2014). Given these findings, interpersonal relationships appear to be an important factor when responding to difficult to manage behaviour. This is supported by research by Wanless and Jahoda (2005) who suggest, in their study, a more complex and dynamic interpersonal appraisal in that paid carers are not typically responding to an isolated behavioural incident, but are instead guided by their past experience, interpersonal history and knowledge of the person they care for. Therefore, in line with this, the themes highlighted in the current study suggest that Weiner's model may not be flexible enough as a framework to examine family carers' willingness to help or their practical responses to behaviours that challenge. Future research would benefit from devising more flexible models to better explain and integrate the factors that may influence family carer's practical responses, or 'helping' behaviour.

Additional factors that influence family carers' experiences of looking after a relative with behaviours that challenge.

'Teamwork' emerged as an important inductive theme in this study. Participants described the support they received from their spouses as valuable within their caring role. This spousal support also helped them when responding to a behavioural incident. Previous research has demonstrated that ongoing encouragement from a spouse can help to reduce the negative impact of caring, not just for parents of typically developing children (Erel & Burman, 1995; Holloway, Suzuki, Yamamoto, & Behrens, 2005) but also for parents of children with an ID (Floyd & Gallagher, 1997). To the researcher's knowledge, there is a lack of studies that have discussed the role of spousal support in couples looking after their adult relative with behaviours that challenge. However, one study (Hassal, Rose & McDonald, 2005) did find that family support for mothers of young children with an ID was an effective coping resource, particularly for those mothers who believed that the

management of the behaviour was within their parental control. Locus of control and parental self-efficacy (Lloyd & Hastings, 2009) are concepts which are said to influence parental attributions, wellbeing and the behaviour of an individual. Family carers' perceptions of their own self-efficacy during difficult to manage behaviour was not explored in this study, however this would offer an important avenue for future research and would assist further with understanding carer helping behaviour. Future research would also benefit from exploring whether spousal support may act as a mediator for how family carers respond at times of behaviours that challenge.

Using an inductive approach, 'support from others' was also identified as an important theme and was divided into two sub-themes; 'why must we fight?' and 'one size does not fit all'. Participants reflected solely on the available support for their adult relative, neglecting their own personal support needs as a carer, which is consistent with previous research in this area (Griffith & Hastings, 2014; Wodehouse & McGill, 2009). Participants described difficulties accessing support for their relative when needed, which resulted in them feeling that they had no option but to become more vocal and assertive in order for their request for support to be heard. When services were then offered, the majority of participants felt that this was still insufficient for their relative's care needs. This dissatisfaction with the support provided by statutory services is reflected throughout the relevant literature in this area (McGill, Tennyson & Cooper, 2006; Griffith & Hastings, 2014). McGill et al. (2006) conducted a review of the perceived helpfulness of professional support for families of children with an ID. Their review found that more studies indicated a negative opinion of the input received than studies that reported that this had been helpful. A number of participants in the present study further expressed frustration at the unresponsiveness of services to the ever-changing needs of their relative, which is arguably vital given the complex and dynamic nature of behaviours that challenge. Participants in this study had not received an individualised and targeted intervention to help them to manage the behaviours displayed by their relative, despite positive behaviour support (PBS) being a well-known model of intervention in formal ID settings. This is supported by a lack of studies overall involving family carers and PBS. The reasons for this are unclear, although it could be hypothesised that because PBS requires a level of objectivity, the close and emotional relationships that participants have with their relative may make this more difficult for them to implement than more objective individuals, such as paid carers. This theme highlighted shortcomings by services when considering supports for family carers responding to difficult to manage behaviour. A more appropriate and acceptable approach should be for services to focus on building good engagement and positive relationships with family carers, ensuring that their opinions are heard and they

feel supported in their caring role, prior to being provided with a behavioural intervention or being offered practical support. This may in fact be more important for family carers.

'The impact of caring' also emerged as an important inductive theme and was divided into two sub-themes; 'the long-term personal impact of caring' and "fears about the future – the dilemma'. For participants, there is a clear emotional and social impact of their caring role, which again is consistent with previous research. Participants described, due to the nature of their ongoing caring role, having to sacrifice time together to socialise as a couple. Having dedicated time to spend one to one with their spouse, other children and their wider social network out with the demands of their caring role is something participants placed value on, but rarely managed to achieve. In order for this to be addressed, services should offer flexible, responsive and easily accessible respite support when required. Having this would allow carers to spend this time socialising with others and restoring their energy, thus enabling them to continue to care for their relative. In addition, studies have found that family carers can experience stress and feelings of burden when caring for their relative (Hastings, 2002; Baker et al. 2003; Herring et al. 2006; Baker, Seltzer & Greenberg, 2012). Participants described a number of ways in which they cope with the emotional impact of caring, which included remaining task focused as a distraction from thinking about their role and continually putting their relative's needs before their own. Studies that have investigated coping strategies and emotional wellbeing in parents of children with an ID have discussed the use of avoidance coping, which relates to a person's cognitive attempts to avoid confronting problems and behaviour. It is a common coping response when a person feels that the circumstance in which they are in cannot be altered and are not within their control (Choi et al., 2012; Blalock et al., 2000). This was a noticeable coping strategy used by the participants in this study. Research exploring an acceptance and mindfulness-based group programme for paid carers looking after adults with an ID and behaviours that challenge (McConnachie, McKenzie, Morris & Walley, 2014) have shown good outcomes in reducing the emotional impact associated with this caring role. Given that participants in this study experience similar stresses to other types of carers, adapting this intervention for family carers would also be important in addressing the long-term impact of caring. In addition, a group programme would have the added benefit of connecting family carers with others who are in a similar caregiving situation. It would also be important for any group programme to include advice and support for family carers to consider future-planning in the event they were no longer able to continue to care for their adult relative at home. Across all accounts, future planning was met with apprehension with the primary concern of participants being that services would not be able to provide the same level of care for their relative as they do, particularly at times of behaviours that challenge. This is

consistent with the literature in this area (Eley, Boyes, Young & Hegney, 2009; Pryce et al., 2017). Participants believed that the love, protection and understanding they can and do provide for their relative, both in general, and at times of behaviours that challenge, cannot be replicated elsewhere by paid carers. This means that a number of participants will choose to continue to care for their relative, despite the long-term negative impact on their emotional and social wellbeing. Future research would benefit from exploring family carers' experiences of considering future planning for their adult relative. This should involve taking into account the perceived barriers and strengths of services ability to embody their family values, and also considering the views of adult relative's and their involvement in this difficult decision-making process.

Strengths and limitations

While this study provided valuable insight into the lived experience of family carers' looking after an adult relative with an ID and behaviours that challenge, there are a number of limitations. Firstly, the sample was purposive with the aim of identifying individuals with the particular experience of caring for an adult relative with an ID and behaviours that challenge. IPA is a useful analytical process for this and for developing complex and interrelated themes, however the themes developed in this study are specific to the accounts of the participants only, and are therefore not representative of the general population. Secondly, a potential limitation with regard to the sample is the range of behaviours that challenge that participants had experience of. Previous research has found that different types of behaviours that challenge can influence how a carer responds during a behavioural incident (Jones & Hastings, 2003), however it has also been argued that categorising behaviour into a single form is not representative of the ID population. In real life, many presentations of behaviours that challenge do co-exist, which is consistent with the findings (Qureshi, 1994). Similarly, given the high co-morbidity of other physical and mental health conditions associated with ID, participants were not excluded if their relative had other diagnoses in addition to their ID. Thirdly, the study aimed to explore the experience of family carers, however, a limitation is that all participants who contacted the researcher to take part were parents, therefore future research would benefit from capturing the experiences of the wider family network (e.g. siblings, grandparents and extended family members) as they too are an important support for adults with an ID and behaviours that challenge. Future research would also benefit from considering the perspective of the adult with an ID, in particular their own personal view of their familial relationships and their experience of living with behaviours that challenge. Fourthly, the potential for volunteer bias is another important limitation of this study. Those who hold greater interest in the

study topic or who have practical support from statutory services for their relative are more likely to participate. Future studies would benefit from recruiting family carers who do not typically use services, and who are otherwise "hard to reach". Approaching informal parenting support groups in the future may minimise this bias.

Finally, the subjective stance of the researcher is important to consider as it will influence the development of the research questions, the interview protocol, and facilitation of each interview. Smith et al. (2009) stated that there can be multiple different reflections and interpretations of data and that the aim of IPA is to encourage the reader to make their own interpretations of what the researcher has highlighted of the participants experience. Unfortunately, no reflective diary was kept, rather regular conversations took place with supervisors regarding the researcher's interpretations of the data throughout all stages of the study. Keeping a reflective diary would have been a helpful measure of the influence of subjectivity in this study. Despite this, the in-depth analysis of data presented in this study is very much relevant in informing the practice, policy and future research related to this under-researched population.

Conclusion

In conclusion, this study explored family carers' experiences of looking after an adult relative with an ID and behaviours that challenge, using Weiner's Attributional Model of Helping Behaviour (1985) as a framework for qualitative research. Participant's described multiple and conflicting attributions at times of difficult to manage behaviour, but generally such behaviour was viewed as not being within their relative's control. Participants predominately described experiencing anger during difficult to manage behaviour, not just in relation to their own discomfort about the situation, but the perceived judgement from members of the public. Both spousal support and the quality of the relationship they have with their relative, positively influenced participant's attributions, emotional reactions and helping behaviour. It was clear that their love and affection enabled them to continue to support and care for their relative, despite the limited available support from statutory services and in spite of the significant emotional and social impact of their caring commitment. This study highlighted the need to explore the experience of family carers further within an interpersonal context (e.g. taking into account the prior knowledge, and quality of the relationship, that the family carer has with the person cared for) as linear models, such as Weiner's model, provide an oversimplified representation of how carers' respond at times of behaviours that challenge.

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Appendix A: Guidelines for submission to Journal of Mental Health in Intellectual Disability Research

About the Journal

Journal of Mental Health Research in Intellectual Disabilities is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

Journal of Mental Health Research in Intellectual Disabilities accepts the following types of article: original articles.

The JMHRID, the official research journal of NADD, is an interdisciplinary research journal with the purpose of reporting original scientific and scholarly contributions to advance knowledge about mental health issues among persons with intellectual disabilities. The journal will address issues related to the full range of psychopathology among persons with intellectual disabilities (mental retardation), neuro-developmental disorders, and autism spectrum disorders, including severe behavior problems, criminality, substance abuse, and genetic phenotypes across the life span. The journal seeks to publish contributions with an emphasis on empirically-based research and will include research on characteristics of persons with intellectual disabilities and mental health problems; risk and protective factors related to the development and/or prevention of mental health problems in persons with intellectual disabilities; development of screening and diagnostic instruments; effectiveness of behavioral, psychosocial and pharmacological treatment procedures; critical or comparative literature reviews, including quantitative meta-analyses. Occasional conceptual reviews that provide for new understanding of theory or theoretical constructs will also be considered.

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Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

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Appendix B: References of studies that were excluded during screening process for systematic review

Number	Reference	Reason for exclusion
1	Bromley, J., & Emerson, E. (1995). Beliefs and emotional reactions of care staff working with people with challenging behaviour. *Journal of Intellectual Disability Research : JIDR, 39* (4), 341–352.	**Not investigating Weiner's model**
2	Cudre-Mauroux, A. (2010). Staff attributions about challenging behaviours of people with intellectual disabilities and transactional stress process: A qualitative study. *Journal of Intellectual Disability Research, 54* (1), 26–39.	**No quantitative measure of attributions, emotions or helping behaviour**
3	Dagnan, D., Hull, A., & McDonnell, D. (2013). The Controllability Beliefs Scale used with carers of people with intellectual disabilities: Psychometric properties. *Journal of Intellectual Disability Research, 57* (5), 422–428	**Development of controllability measure**
4	Dilworth, J. A., Phillips, N., & Rose, J. (2011). Factors relating to staff attributions of control over challenging behaviour. *Journal of Applied Research in Intellectual Disabilities, 24* (1), 29–38	**Investigating factors influencing carer attributions**
5	Drysdale, E. E., Jahoda, A., & Campbell, E. (2009). Investigating spontaneous attributions in mothers of individuals with intellectual disabilities and self-injurious behaviour. *British Journal of Learning Disabilities, 37* (3), 197–206.	**Not investigating Weiner's model**
6	Edelstein, T. M., & Glenwick, D. S. (2001). Direct-care workers' attributions of psychopathology in adults with mental retardation. *Mental Retardation, 39* (5), 368–378.	**Not investigating Weiner's model**
7	Edelstein, T. M. (2000). Direct-care workers' attributions of psychopathology in adults with mental retardation. *Dissertation Abstracts International: Section B: The Sciences and Engineering, 60* (8), 4218.	**Unpublished**
8	Grey, I. M., McClean, B., & Barnes-Holmes, D. (2002). Staff attributions about the causes of challenging behaviours: effects of longitudinal training in multi-element behaviour support. *Journal of Learning Disabilities, 6* (3), 297–312.	**Investigating the effects of staff training**
9	Hare, D. J., Durand, M., Hendy, S., & Wittkowski, A. (2012). Thinking about challenging behavior: A repertory grid study of inpatient staff beliefs. *Intellectual and Developmental Disabilities, 50* (6), 468–478.	**Not investigating Weiner's model**

10	Hartley, S. L., Schaidle, E. M., & Burnson, C. F. (2013). Parental attributions for the behavior problems of children and adolescents with autism spectrum disorders. *Journal of Developmental and Behavioral Pediatrics, 34* (9), 651–660.	**Included children and adolescents with autism spectrum disorder and no intellectual disability**
11	Hastings, R. P. (1997). Measuring staff perceptions of challenging behaviour: the challenging behaviour attributions scale (CHABA). *Special Issue: Mental Health and Intellectual Disability, 41* (6), 495–501.	**Development of attributional measure**
12	Hastings, R. P. (1997). Staff disbeliefs about the challenging behaviors of children and adults with mental retardation. *Clinical Psychology Review, 17* (7), 775–790.	**Literature review**
13	Hastings, R. P., Remington, B., & Hopper, G. M. (1995). Experienced and inexperienced health care workers' beliefs about challenging behaviours. *Journal of Intellectual Disability Research : JIDR, 39* (6), 474–483.	**Not investigating Weiner's model**
14	Hastings, R. P., Reed, T. S., & Watts, M. J. (1997). Community staff causal attributions about challenging behaviours in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 10* (3), 238–249.	**Not investigating Weiner's model**
15	Hyman, P., & Oliver, C. (2001). Causal explanations, concern and optimism regarding self-injurious behaviour displayed by individuals with cornelia de lange syndrome: the parents' perspective. *Journal of Intellectual Disability Research, 45* (4), 326–334.	**Not investigating Weiner's model**
16	Jacobs, M., Woolfson, L. M., & Hunter (2016). Attributions of stability, control and responsibility: how parents of children with intellectual disabilities view their child's problematic behaviour and its causes. *Journal of Applied Research in Intellectual Disabilities, 29* (1), 58–70.	**Not investigating Weiner's model**
17	Jahoda, A., & Wanless, L. K. (2005). Knowing you: the interpersonal perceptions of staff towards aggressive individuals with mild to moderate intellectual disabilities in situations of conflict. *Journal of Intellectual Disability Research, 49* (7), 544–551.	**Not investigating Weiner's model**
18	Lambrechts, G., & Maes, B. (2009). Analysis of staff reports on the frequency of challenging behaviour in people with severe or profound intellectual disabilities. *Research in Developmental Disabilities, 30* (5), 863–872.	**Not investigating Weiner's model**
19	Lancaster, R. L., Balling, K., Hastings, R., & Lloyd, R. (2014). Attributions, criticism and	**Not investigating Weiner's model**

	warmth in mothers of children with intellectual disability and challenging behaviour: a pilot study. *Journal of Intellectual Disability Research, 58* (11), 1060–1071.	
20	MacKinlay, L., & Langdon, P. E. (2009). Staff attributions towards men with intellectual disability who have a history of sexual offending and challenging behaviour. *Journal of Intellectual Disability Research*, *53* (9), 807–815.	**Offending behaviour**
21	Noone, S. J., Jones, R. S. P., & Hastings, R. P (2006). Care staff attributions about challenging behaviors in adults with intellectual disabilities. *Research in Developmental Disabilities*, *27* (2), 109–120	**Not investigating Weiner's model**
22	Poppes, P., van der Putten, A. A. J., ten Brug, A., & Vlaskamp, C. (2016). Staff attributions of the causes of challenging behaviour in children and adults with profound intellectual and multiple disabilities. *Research in Developmental Disabilities*, *48*, 95–102.	**Not investigating Weiner's model**
23	Smith, M., & Willner, P. (2004). Psychological factors in risk assessment and management of inappropriate sexual behaviour by men with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *17* (4), 285–297.	**Not investigating Weiner's model**
24	Snow, E., Langdon, P. E., & Reynolds, S. (2007). Care staff attributions toward self-injurious behaviour exhibited by adults with intellectual disabilities. *Journal of Intellectual Disabilities*, *11* (1), 47–63.	**Investigating burnout**
25	Tynan, H., & Allen, D. (2002). The impact of service user cognitive level on carer attributions for aggressive behaviour. *Journal of Applied Research in Intellectual Disabilities*, *15* (3), 213–223.	**Not investigating Weiner's model**
26	Watts, M. J., Reed, T. S., & Hastings, R. P. (1997). Staff strategies and explanations for intervening with challenging behaviours: a replication in a community sample. *Journal of Intellectual Disability Research, 41* (3), 258–263.	**Not investigating Weiner's model**
27	Whittington, A., & Burns, J. (2005). The dilemmas of residential care staff working with the challenging behaviour of people with learning disabilities. *British Journal of Clinical Psychology*, *44* (1), 59–76.	**Qualitative methodology (IPA)**
28	Williams, S., Dagnan, D., Rodgers, J., & Freeston, M. (2015). Exploring carers' judgements of responsibility and control in response to the challenging behaviour of people with intellectual disabilities. *Journal*	**No measure of helping behaviour**

	of Applied Research in Intellectual Disabilities, 28 (6), 589–593.	
29	Willner, P., & Smith, M. (2008). Attribution theory applied to helping behaviour towards people with intellectual disabilities who challenge. *Journal of Applied Research in Intellectual Disabilities, 21* (2), 150–155.	**Literature review**
30	Ziljman, L., Embregts, P., Bosman, A., & Willems, A. P. (2012). The relationship among attributions, emotions, and interpersonal styles of staff working with clients with intellectual and challenging behavior. *Research in Developmental Disabiltiies, 33*, 1484-1494.	**No measure of helping behaviour**

Appendix C: Systematic Review Quality Criteria

Quality Criteria for Systematic Review

Quality criteria for this systematic review was developed using STROBE and CRD guidance.

Key

Well addressed	The quality criterion is fully addressed and clearly reported
Adequately addressed	The quality criterion is partly addressed and adequately reported. Further information is required
Poorly addressed	The quality criterion is insufficiently addressed and reported. Substantial information is required.
Not addressed	The quality criterion was not addressed or reported. There is an absence of relevant information.
Not applicable	The quality criterion and the information reported was not applicable.

Author:

Year:

1. Study design

1.1 Study aims and hypotheses

Well addressed	The aims and hypotheses were appropriate, based on a theoretically robust rationale and clearly defined
Adequately addressed	The aims and hypothesis were based on a theoretically robust rationale, but they were only briefly reported or were

	unclear, but they could still be inferred from the rationale presented
Poorly addressed	The aims and hypotheses were inappropriate and insufficiently described with little theoretical rationale OR the theoretical literature was misinterpreted by the author/s.
Not addressed or not applicable	The quality criterion was not addressed or reported. There is an absence of relevant information or the quality criterion and the information reported was not applicable.

1.2 Ethical considerations

Well addressed	The study reported that it was subject to independent ethical review.
Not addressed	The study did not report that it was subject to independent ethical review.

2. Sample

2.1 Participants selected are representative of those working with people with an intellectual disability and behaviours that challenge

Well addressed	Participants selected are completely representative and clearly reported. The study clearly states that the participants have experience of looking after someone with an intellectual disability and behaviours that challenge.
Adequately addressed	Participants selected are partially representative and is adequately reported. The study states that the participants have experience looking after someone with an intellectual disability, but the nature of

	their experience of behaviours that challenge is not clear
Poorly addressed	Participants selected are not representative or participant's experience of looking after someone with an intellectual disability and behaviours that challenge are not clearly reported, but can be inferred from the literature.
Not addressed or not applicable	The quality criterion was not addressed or reported. There is an absence of relevant information or the quality criterion and the information reported was not applicable.

2.2 Participants demographics reported

Well addressed	Demographic information is fully described (age, gender, role, setting, experience etc.).
Adequately addressed	Demographic information is largely described (e.g. at least three characteristics).
Poorly addressed	Demographic information is not well described (e.g. less than two characteristics).
Not addressed or not applicable	The quality criterion was not addressed or reported. There is an absence of relevant information or the quality criterion and the information reported was not applicable.

2.3 Response rate

Well addressed	The number of participants invited to take part and the response rate were reported.

	Response rate was reflected upon e.g. in comparison to other similar studies
Adequately addressed	The number of participants invited to take part and the response rate were reported. Response rate was not reflected upon e.g. compared to other similar studies
Poorly addressed	Either the number of participants invited to take part or the response rate was reported, but not both. Response rate was not reflected upon.
Not addressed or not applicable	The quality criterion was not addressed or reported. There is an absence of relevant information or the quality criterion and the information reported was not applicable.

3. Measures used

3.1 Method of eliciting carer responses

Well addressed	The study asks participants to provide a detailed account of a real life event or the study uses written or video accounts to represent behaviours that challenge which have a full details of the topography of the behaviour.
Adequately addressed	The study uses written, video accounts to represent behaviours or real life events, but details of the topography of the behaviour are limited.
Poorly addressed	Study reports that an appropriate method of stimuli was used but no information with regard to the topography of the behaviours that challenge.
Not addressed or not acceptable	The quality criterion was not addressed or reported. There is an absence of relevant

	information or the quality criterion and the information reported was not applicable.

3.2 Quality of the measures used to address Weiner's Attributional Model of Helping Behaviour (1985)

Well addressed	Measures which address all of the variables of interest in Weiner's model (e.g. attributions, emotional reactions and helping behaviour). Choice of measures are justified. Previous research is referenced.
Adequately addressed	Measures which address some, but not all of the variables of interest in Weiner's model (attributions, emotional reactions and helping behaviour). Choice of measures are adequately justified. Previous research is referenced.
Poorly addressed	Little or no information about the measures used. Choice of measures are not justified with reference to prior research or are unreliable/not valid.
Not addressed or not applicable	The quality criterion was not addressed or reported. There is an absence of relevant information or the quality criterion and the information reported was not applicable.

4. Analysis

4.1 Power calculation

Well addressed	A power calculation was conducted and reported. The power and sample size were

	deemed to be sufficient enough for the study design and analysis
Not addressed or not applicable	A power calculation was not addressed or reported. There is an absence of relevant information or the quality criterion and the information reported was not applicable.

4.2 Statistical analysis

Well addressed	Statistical analyses were clearly reported and appropriate for the research question and study design. Advanced analysis, such as mediation analysis, was used to explore the variables of interest in Weiner's model.
Adequately addressed	Statistical analysis was largely described and appropriate for the research question and study design, with sufficient detail to allow for replication. Planned analysis (e.g. regression or correlational analysis was used to explore at least two of the variables of interest in Weiner's model.
Poorly addressed	Statistical analysis was not reported, appropriate or unclear. Correlational analysis was not used to explore at least two variables in Weiner's model.
Not addressed or not applicable	The quality criterion was not addressed or reported. There is an absence of relevant information or the quality criterion and the information reported was not applicable.

5. Results

5.1 Conclusions

Well addressed	Conclusions were clearly reported, appropriate and in line with the study findings, taking in to account the sample, sample size, methodology etc. Conclusions regarding the generalisability of the study was clear and appropriate. Clinical implications were detailed.
Adequately addressed	Conclusions were adequately reported and largely appropriate, but the author/s under or over stated their findings, including their conclusions regarding generalisability.
Poorly addressed	Conclusions were poorly reported or inappropriate and not in line with the study findings.
Not addressed or not applicable	The quality criterion was not addressed or reported. There is an absence of relevant information or the quality criterion and the information reported was not applicable.

5.2 Study limitations

Well addressed	Limitations (e,g. potential biases) and implications for the study findings were clearly reported. Possible future avenues for research are discussed.
Adequately addressed	Limitations and implications for the study findings were adequately reported and addressed. Future avenues for research are discussed, but vague.

Poorly addressed	Limitations and implications for the study findings were insufficiently reported or not mentioned.
Not addressed or not applicable	The quality criterion was not addressed or reported. There is an absence of relevant information or the quality criterion and the information reported was not applicable.

6. Conflicts of interest

6.1. Conflicts of interest and source of funding addressed

Well addressed	Sources of funding and conflicts of interest were declared. The role of the funders in the research is clear.
Not addressed	Sources of funding and conflicts of interest were not declared. The role of the funders in the research is not clear.

- End of Quality Criteria for Systematic Review –

Appendix D: Confirmation of University of Edinburgh Ethical Approval

School of Health in Social Science
Clinical and Health Psychology

The University of Edinburgh
Medical School
Doorway 6, Teviot Place
Edinburgh EH8 9AG

Telephone 0131 651 3969
Fax 0131 650 3891
Email submitting.ethics@ed.ac.uk

Liam Mooney
Trainee Clinical Psychologist (DClinPsychol)
Department of Clinical and Health Psychology
School of Health in Social Science
University of Edinburgh

30 July 2019

Dear Liam,

Application for Level 2 Approval

Reference: CLIN659
Project Title: The qualitative experiences of families looking after an adult relative with an intellectual disability and behaviours that challenge
Academic Supervisor: Monja Knoll

Thank you for submitting the above research project for review by the Department of Clinical and Health Psychology Ethics Research Panel. I can confirm that the submission has been independently reviewed and was approved on the 28th July 2019.

Should there be any change to the research protocol it is important that you alert us to this as this may necessitate further review.

Yours sincerely,

Kirsty Gardner

Administrative Secretary
Clinical Psychology

Appendix E: Confirmation of Sponsorship Review

University of Edinburgh
College of Arts, Humanities and Social Sciences
Research Governance Office
55 George Square
Edinburgh
EH8 9JU

9th July 2019

Liam Mooney
c/o School of Health in Social Sciences
University of Edinburgh

Dear Liam,

Study Title: The qualitative experiences of families looking after an adult relative with an intellectual disability and behaviours that challenge

Sponsor number: CAHSS1907/01

Under the requirements of the UK policy framework for health and social care research the University of Edinburgh agrees in principle to act as Sponsor for this project. Sponsorship is subject to you obtaining institutional ethics for the project.

As Chief Investigator, you must ensure that the study does not commence until all applicable approvals have been obtained. Following receipt of all relevant approvals, you should ensure that any amendments to the project are notified to the Sponsor.

Yours sincerely

Charlotte Smith

Research Governance Coordinator

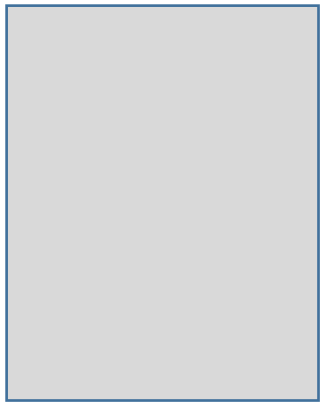
Appendix F: Participant Information Sheet

THE UNIVERSITY of EDINBURGH

Participant Information Sheet

Study title: The qualitative experiences of families looking after an adult relative with an intellectual disability and behaviours that challenge.

My name is Liam Mooney and I am undertaking a study as part of my Doctorate in Clinical Psychology. I also work in the NHS Forth Valley Psychological Therapies Service with adults with an intellectual disability (also known as a learning disability) and their families.



You are being invited to take part in a study. Before you decide whether or not 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 this carefully and feel free to contact me if there is anything that is not clear or if you would like more information. Do take your time to decide whether or not you wish to take part and talk to others about the study, if you wish.

What is the purpose of the study?

To explore family members views and lived experience of looking after their adult relative with an intellectual disability (ID) and behaviours that challenge. I hope to meet with 10 to 12 family members between July 2019 and February 2020. Findings from this study aim to highlight carer support needs that are not always met by services and help to improve the delivery of evidenced-based interventions for behaviours that challenge.

Why have I been invited?

You have been invited to participate in this study because;

- You are a family carer. This means you are, for example a parent, adoptive parent, grandparent or sibling
- You care for your relative with an ID at home.
- Your relative can display behaviours that may be described as challenging.

Do I have to participate?

No, not at all. If you do not wish to take part in the study, you do not need to contact the researcher or return the contact slip provided. If you decide to take part, you are still free to change your mind, both before and during the meeting. ***Choosing not to take part or withdrawing from the study will not affect the care you or your relative will receive from services.***

If you do decide to take part, you will still be able to withdraw from the study until approximately one month before completion of the study. After this time all data will be anonymised so it will not be possible to identify your data. You can withdraw before January 2020 by contacting the researcher using the contact details provided at the end of this information sheet.

What will I have to do?

If you choose to participate in this study, there are a few ways you can get in contact. You can contact me directly on 01324 614 347 or email s0831439@sms.ed.ac.uk. Alternatively, you can complete the contact slip at the end of this information pack and return it in the reply-paid envelope to be contacted. Once you have made contact, I will talk to you by telephone and answer any questions you may have and if you are happy a meeting will be arranged at a date and time that is convenient to you in the Falkirk area or over telephone or Skype. When you meet with myself you will be asked to sign a consent form stating that you wish to participate in the study.

Participation involves us having a conversation (in person, over the phone or through Skype) that will last approximately 40 to 60 minutes. You will be invited to talk about your experience in general of looking after your relative with an ID, the impact of your caring situation, your experience of the supports available to you and your families and your experience of responding to behaviours that challenge. You will also be offered a phone call follow-up 5 days after our meeting to check in and answer any questions you may have.

Please note: *at this meeting, everything we talk about is kept private and confidential, however, if you raise concerns about your relative's behaviour that this is causing you and/or your relative significant distress (e.g. a risk of harm to yourself, your relative, family member or members of the public) then I have a professional duty of care to support you to seek relevant supports if required. I can also offer information about accessing relevant local services.*

Will my taking part in the study be kept confidential?

Your data will be processed in accordance with Data Protection Law (GDPR, 2018). All information about you will be kept strictly confidential. The interviews will be recorded on a digital audio device, and will then be transcribed with the removal of any identifiable information. Interview transcripts will be safely stored at the University of Edinburgh and only authorised people will have access to them. Interview transcripts will be destroyed after the end of this study. As standard with this type of research, short anonymised quotations will be used within the write-up; it will not be possible to identify you or your relative from the quotation.

For more information about how we use your data please go to:
https://www.ed.ac.uk/records-management/privacy-notice-research

What are the possible disadvantages and risks of taking part?

It is possible that you might feel upset when talking about caring for your relative. If you do feel upset please let me know. You can stop the interview at any point if you feel upset. There is also information about support available to you at the end of this sheet. As mentioned, taking part in the study will take 40 to 60 minutes of your time and may involve travel to take part in the interview.

What are the possible benefits of taking part?

It is hoped that by taking part in this research, you will be providing valuable information about the experience of looking after an adult with an ID. This will be extremely helpful for highlighting potential carer support needs that are not always met by services and to help to improve the delivery of evidenced-based interventions for behaviours that challenge.

What will happen to the results of the study?

The overall findings will be written up as part of my Doctorate in Clinical Psychology. It will also be submitted for publication in a relevant peer-reviewed journal and shared with other researchers and health professionals to help improve services for adults with an ID. All published information will be anonymised.

Who has reviewed this study?

The study proposal has been reviewed by the University of Edinburgh Ethics Review Board and given a favourable ethical opinion.

How do I get a copy of the results of the study?

A summary of the findings can be provided after March 2020 when the study will be completed. Relevant contact details are outlined below.

If you have any questions or concerns regarding the above, then please do not hesitate to contact;

Liam Mooney

School of Health in Social Science
University of Edinburgh
Teviot Place
Edinburgh
EH8 9AG

Tel: 01324 614 347
Email: s0831439@sms.ed.ac.uk

You can also contact the academic supervisor for this study;

Dr Monja Knoll

School of Health in Social Science
University of Edinburgh
Teviot Place

Edinburgh
EH8 9AG

Tel: 0131 650 3481
Email: monja.knoll@ed.ac.uk

To speak with someone outwith the research team, please contact;

Dr Angus MacBeth

School of Health in Social Science
University of Edinburgh
Teviot Place
Edinburgh
EH8 9AG

Tel: 131 650 3893
Email: angus.macbeth@ed.ac.uk

If you wish to make a complaint about the study, please contact;

Professor Matthias Schwannauer
Head of School, School of Health in Social Science
University of Edinburgh

Tel: 0131 650 4327.

If you wish to raise a complaint on how we have handled your personal data you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO) at https://ico.org.uk/

Data Protection Officer contact information:

University of Edinburgh
Data Protection Officer
Governance and Strategic Planning
University of Edinburgh
Old College
Edinburgh
EH8 9YL
Tel: 0131 651 4114
dpo@ed.ac.uk

Useful contact information

Information taken from Scottish Government website, support for carers (https://www.mygov.scot/carer-support; 1st September 2018).

Carer advice, advocacy and support:

Care Information Scotland
Provides information about care services for people living in Scotland.
Tel: 08456 001 001 Website: www.careinfoscotland.scot

Carers Trust Scotland
Aims to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend.
Tel: 0300 123 2008
Email: scotland@carers.org Website: www.carers.org/country/carers-trust-scotland

Carers Scotland
Gives expert advice, information and support to unpaid carers.
Tel: 0141 445 3070
Email: info@carerscotland.org Website: www.carersuk.org

Shared Care Scotland
Works to improve the quality and provision of short breaks for carers in Scotland.
Tel: 01383 622 462
Email: office@sharedcarescotland.com Website: www.sharedcarescotland.org.uk

Scottish Independent Advocacy Alliance
Offers independent advocacy support to any vulnerable person in Scotland.
Tel: 0131 524 1975
Email: enquiry@siaa.org.uk Website: www.siaa.org.uk

MECOPP Carers Centre
Supporting minority ethic carers to access supports and services that suit their caring situation.
Tel: 0131 467 2994
Email: info@mecopp.org.uk Website: https://www.mecopp.org.uk

Health and wellbeing:

Breathing Space
Offers individual support and advice if you need someone to talk to.
Tel: 0800 83 85 87 Website: www.breathingspace.scot

Samaritans
Provides emotional support via telephone to anyone in emotional distress and struggling to cope.
Tel: 116 123 Website: www.samaritans.org

Appendix G: Consent Form

Consent Form

Study title: Qualitative experiences of families looking after an adult relative with an intellectual disability and behaviours that challenge

Name of researchers: Liam Mooney, Dr Monja Knoll, Dr Sharon Horne-Jenkins

	Please initial
I confirm that I have read and understand the information sheet (Version No: 2 Date: 27.09.2019) for the above study. I have had the opportunity to consider the information, ask questions and have had sufficient time to decide whether to take part in this study.	
I understand that my participation is voluntary and that I am free to withdraw at any time up until one month prior to the completion of the study, without giving any reason, without my legal rights being affected. This will also not affect the care I or my relative will receive from services.	
I consent to my interview being audio recorded on an encrypted digital audio recorder and transcribed.	
I understand and agree that some quotations from my interview may be contained within a doctoral thesis project and may be used in publications that arise from this thesis. I understand that any quotations will be anonymised and I or my relative will not be identifiable.	
I understand that relevant sections of data collected during the study may be looked at by individuals from the Sponsor (University of Edinburgh) where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.	
I agree to take part in the above study.	

Name of participant	Date	Signature
Name of person taking consent	Date	Signature

Original (x1) to be retained in site file Copy (x1) to be retained by participant

Appendix H: Participant Demographic Information Form

Demographic Information Sheet

QUESTIONS ABOUT YOU:

Age: **Gender:**

What is your relationship to your relative with an intellectual disability? _____

Marital Status *please circle***:**

Single Married Divorced Separated Widowed

Family supports *please circle as many as are applicable?***:**

Extended family Voluntary Agencies Social Work

Community Learning Disability Team Other *please specify*: _____

How long have you cared for your relative with an intellectual disability? _____

QUESTIONS ABOUT YOUR RELATIVE WITH AN INTELLECTUAL DISABILITY

Age: **Gender:**

Level of disability (if you know):

Appendix I: Semi-Structured Interview Schedule

INTERVIEW SCHEDULE

Introduction:

- *Introduction*
- *Clarifying last minutes enquiries about study*
- *Emphasise confidentiality.*
- *I want you to talk about your experiences of caring for your relative; there are no right or wrong answers. First, can I ask you to fill out this short form about you (administer demographic information sheet).*

1. **Tell me about X?**

(Follow-up: How would you describe X? What is your relationship like with X? How would you describe your interactions and communication with X?)

2. **What is it like caring for X?**

(Follow-up: Can you give me an example of a typical day with X? How involved are you in X's care? What is it like caring for X now, compared to in the past or in childhood? How do you think you care for X that is different to paid carers?)

3. **Can you tell me about a time when X's behaviour has been challenging?**

(*Follow-up: What was your understanding of X's behaviour? What did you think about X's behaviour? What did you feel at that time? What did you do about X's behaviour? Can you tell me about a time when X's behaviour hasn't been challenging?)*

4. **Does X's behaviour have any impact on you and your family?**

(Follow-up: How do you manage? How does that impact on your relationship with X? How has this impacted on your life (personal, relational, occupational, wellbeing, physical health)? Has this changed as X has got older?)

5. **What is your experience of the support you, your family and X have received in relation to X's behaviour?**

(Follow-up: What are your current supports? Has this changed as X has got older? What interventions have you/do you use/have used? Is there anything you have found helpful or unhelpful?)