THE UNIVERSITY OF HULL

Raising concerns in healthcare services: The experience of staff and families.

being a Thesis submitted in partial fulfilment

of the requirements for the degree of Doctor of Clinical Psychology in the University of Hull

by

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Contents

Acknowledgements

Overview

This portfolio thesis has three parts. Part one is a systematic literature review in which the existing research literature on the psychological and systemic factors that influence healthcare staff's decision to whistleblow on poor care is examined and its quality evaluated. Part two is an empirical paper which uses Interpretative Phenomenological Analysis (IPA; Smith, 1996) to explore the experiences of families of people with intellectual disabilities when noticing and reporting concerns in healthcare services. Part three comprises the Appendices, containing supporting information relating to parts one and two and epistemological and reflective statements.

Total word count for portfolio (excluding references and appendices): 11079

List of Tables and Figures

Part one: Systematic Literature Review

Part two: Empirical Paper

Part One: Systematic Literature Review

Factors affecting Whistleblowing Decisions in Healthcare.

This paper is written in the format ready for submission to the Journal of Adult Protection.

Please see Appendix A. for author guidelines

Word count: 6000

Abstract

Purpose This systematic literature review aimed to investigate the psychological and systemic variables influencing whistleblowing decisions in healthcare settings.

Design/methodology/approach A search of academic databases was undertaken and reference lists of the resulting articles were searched. In total 17 studies using a range of methodologies were analysed using Narrative Synthesis. Methodological quality was assessed. ***Findings*** Psychological variables were grouped into beliefs about advocacy and professional roles, fear and diverse responses to wrongdoing. Systemic variables were grouped into relationships with peers, the culture of the organisation and feedback, however there was a complex interplay of factors.

Research Implications Further research is needed to examine the efficacy of these interventions and to represent the views of a wider range of healthcare professionals.

Originality/value This was a timely review given recent reports on the treatment of whistleblowers in healthcare, indicating interventions to facilitate whistleblowing such as increasing the ease of reporting systems, providing feedback and creating a more compassionate organisational culture.

Keywords: adult safeguarding; whistleblowing; healthcare

Background

Recent incidents such as abuse of people with Intellectual Disabilities at Winterbourne View hospital (2011; Department of Health, 2012b for government response) and neglect of patients at Mid Staffordshire NHS Hospitals Trust (2010) highlighted unacceptable care practices, leading to public outrage. The resulting inquiry declared the need to '*ensure openness, transparency and candour throughout the system about matters of concern*' (Francis, 2013; pp 1441). One way to do this is through whistleblowing, defined as '*the disclosure by an individual to the public, or those in authority, of mismanagement, corruption, illegality, or some other form of wrong-doing in the workplace.*' (Health and Care Professionals Council, 2016.). The NHS constitution (Department of Health, 2013) pledges to encourage whistleblowers and whistleblowers are protected by the Public Interest Disclosure Act (1998).

Despite supportive legislation and policy, a large body of evidence suggests that healthcare staff experience whistleblowing as stressful and isolating with aversive consequences. These include physical and psychological exhaustion, deterioration of mental health, alienation from colleagues, detriment to career progression, suspension, dismissal, stigma when seeking re-employment and financial consequences (McDonald and Ahern, 2000; Jackson et al, 2010). Staff in the Freedom to Speak Up report (Francis, 2015) described a culture of blame, fear and defensiveness within their workplaces. Negative language was often used to refer to those who did speak up (e.g. 'troublemakers' and 'backstabbers'). Whistleblowers were generally not offered support through the process and experienced difficulties upon returning to work. A significant minority never received feedback regarding the outcome of their reporting.

Despite the existence of multiple disincentives, some staff still whistleblow. Literature from professions outside healthcare, such as in business ethics, provides insights on how staff make decisions when faced with an ethical issue at work. A recent review of the empirical ethical decision making literature (Craft, 2013) found a number of studies

focussing on the role of personality or individual factors. People high on hedonism were more likely to be influenced by material rewards to make unethical decisions and individuals with an external locus of control were more likely to make unethical decisions. However this also suggests a large role for systemic variables (influence of others).

Organisational factors such as supervisor support and informal policies encouraging whistleblowing have been found to be significant predictors of whistleblowing (Sims and Keenan, 1998). Sims and Keenan found that studies into cultural differences show the course of action considered most ethical can vary, due to the differing influence of peer groups and values. However there may also be some similarities in how ethical behaviour is defined across cultures.

Models of ethical decision making provide a framework for understanding the process individuals go through. Rest (1986) proposed that ethical decision making involves four psychological processes: moral sensitivity, moral judgement, moral motivation/intention and moral character/action. Moral sensitivity involves recognising an ethical issue, moral judgement requires sorting through the potential options to determine the most ethically sound, moral motivation refers to the intention to choose this option over other less ethical options and moral action involves the behaviour to see this through. Jones (1991) suggested that moral intensity influences each of these decision making stages and has six components: magnitude of consequences, temporal immediacy, social consensus, proximity, probability of effect and concentration of effect.

Although studies from outside of healthcare provide valuable information regarding influences on the decision to whistleblow, there may be some differences between business and healthcare settings. For example in healthcare settings the ethos of organisations may be one of care rather than of primarily profit, and individual motivation to work in this sector may be different. There may be different implications if the decision whether to whistleblow has an impact on the wellbeing or safety of a patient. Therefore this review aims to examine factors impacting whistleblowing

decisions specifically in healthcare settings. The review organises these into psychological and systemic factors as the existing research has generally distinguished between factors relating to the person and factors relating to the system. By increasing understanding of the whistleblowing process, it is hoped that the conditions that foster reporting behaviour can be identified with implications for how organisations can better facilitate this.

Method
Search Strategy

A systematic literature search was undertaken using search terms which were refined and agreed amongst the research team: *psychology** OR *individual* OR *systemic* OR *organisational* AND *Whistleblow**. The online databases searched were PsycINFO, Academic Search Premier, CINAHL Complete and Medline to access research from a broad range of specialities within health and social care. The reference lists of included articles were searched for relevant studies. Quantitative, qualitative and mixed methods studies were included in the review to maximise access to relevant findings.

Inclusion Criteria

The inclusion criteria were (i) written in the English language (funding was not available for translation), (ii) published in an academic peer reviewed journal (to ensure reasonable quality), (iii) qualitative, quantitative or mixed methods design and (iv) pertaining to healthcare settings. Studies were excluded if they did not report original research (i.e. literature reviews). A total of 17 studies were selected, of which seven were quantitative, seven were qualitative and three used mixed methods (see Figure 1).

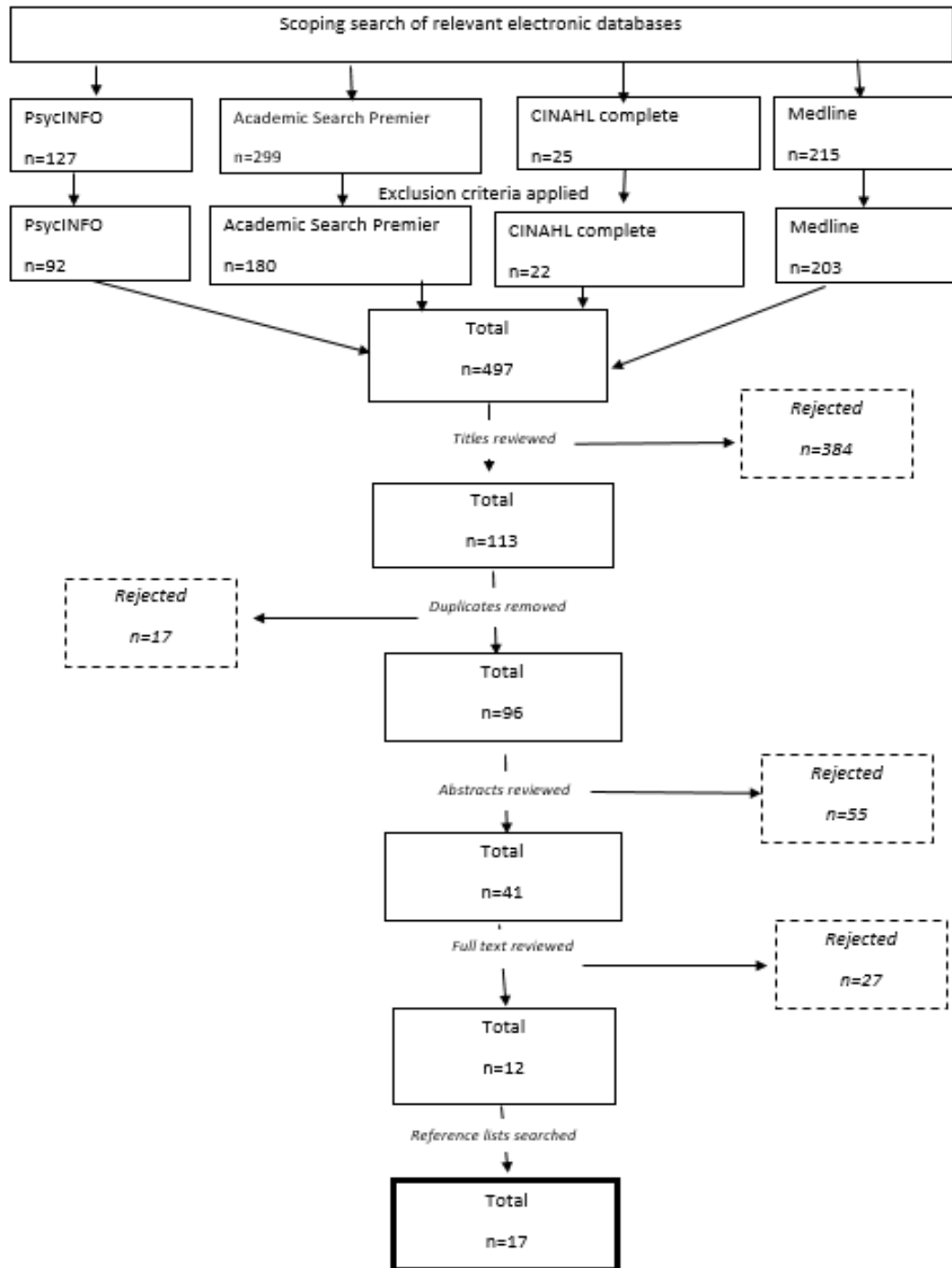Figure 1. Flowchart depicting the study selection process.

Key information from the qualitative studies was extracted using the National Institute for Health and Care Excellence (NICE; 2008) data extraction form. For quantitative and mixed method studies custom forms were devised due to the lack of suitable existing forms (see Appendix B). Quality assessment was undertaken to inform the author as to

the validity of the studies' findings and was carried out using the Mixed Methods Appraisal Tool (MMAT; Pluye et al., 2009; Appendix C). This tool was chosen to facilitate the appraisal of qualitative, quantitative and mixed methods studies to be carried out using one tool, ensuring consistency. In order to assess quality the scores on the relevant areas of the MMAT for each study were totalled and divided by the number of questions to give a percentage ranging from 0% (indicating poor quality) to 100%. To ensure inter-rater reliability, a subset of 5 studies (29.41% of the total sample) were rated independently by a third party researcher. Differences of opinion were discussed until a consensus was reached.

Data Analysis

The data extracted from the studies was analysed using narrative synthesis as this allows qualitative, quantitative and mixed methods studies to be compared. Lucas et al (2007) suggest that narrative synthesis is the most suitable method for reviews which aim to describe the existing body of literature and identify the scope of areas covered as well as examining the strengths and gaps in such literature.

The narrative synthesis process was undertaken in line with guidance developed by Popay et al (2006). Following data extraction the studies were organised according to patterns in the psychological or systemic factors they identified as influencing staff's decision to whistleblow. Textual descriptions of each factor were produced and the studies that had identified that factor were described and compared with one another. Quality assessment ratings contributed to understanding differences in findings between studies. The author sought to order the findings in a logical manner so as to 'tell a story' and to end with an overall assessment of the strength of the evidence.

Results
Of the 17 articles reviewed, seven used quantitative methodology, seven used qualitative and three were mixed methods. Five of the included studies originated in the United Kingdom, four in Australia, three in the United States, four in Asia and one in Saudi Arabia. The majority of the studies featured nurses (n=12), four had samples

comprised of various health and social care employees and one featured medical students (Table 1).

Psychological Factors

Individual beliefs about advocacy and the professional role

A number of studies discussed the importance of professionals' beliefs about patient advocacy, whistleblowing and their role. In many situations the moral cause of action can be ambiguous and people differ in how they appraise incidents. For example Goldie et al. (2003) found that medical students' reasoning about whistleblowing scenarios was not always consistent with professional consensus and instead was often based on the students' own personal values and beliefs. Moore and McAuliffe (2012) found that nurses can be deterred from reporting when an incident seems unclear as they are 'not sure what to do' and worry about 'causing trouble'. Uncertainty about the required standards of care and lack of confidence in one's own judgement lead to fears that concerns might be disbelieved or dismissed (Attree, 2007). Calcraft (2007) stated that care workers may not speak out because they are new to a job, unsure what constitutes abuse and lack appropriate training.

Difficulty deciding whether to report is complicated by beliefs about whether the potentially harmful action was intentional or not. Nurses in King's (2001) study indicated that they would not report wrongdoings they believed to be unintentional, such as a nurse failing to implement medical orders in a timely fashion. The unintentional statements were rated as less serious than the intentional statements which included items such as a nurse threatening a patient. In the case of unintentional wrongdoing, nurses preferred to confront their colleague directly rather than whistleblowing.

Even when a situation was appraised as necessitating reporting, whether staff did was mediated by their perceptions of their professional role. Ahern and McDonald (2002) found that there were differences between whistleblowers and non-whistleblowers in terms of their beliefs about nurses' roles. Whistleblowers were more likely to support

beliefs relating to patient advocacy (e.g. '*a nurse's primary responsibility is to the patient*') whereas non-whistleblowers were more likely to endorse beliefs about the responsibility of a nurse to physician (e.g. '*a nurse is obligated to follow a Physician's order at all times).* They concluded that nurses may respond to incidents from different belief systems and this influences whether or not they decide to report poor care. In some cases it was the professional's belief in their duty to advocate for the patient that sustained them throughout the process of whistleblowing (Jackson and Raftos, 1997). However sometimes there was conflict between the duty to advocate and the fear of repercussions from doing so (Attree, 2007) and this created a sense of failure at feeling unable to advocate (Jackson et al, 2010).

Numerous studies discussed the term 'whistleblowing' and its connotations. Jones and Kelly (2014) reported that the majority of participants in their study perceived the term negatively, associating it with 'telling tales', although a minority were more positive. Participants associated it with serious incidents and personal repercussions. Nurses in Jackson et al's (2010) studies also reflected that whistleblowing was a term that was generally stigmatised and looked upon negatively. This may contribute to the fact that whistleblowing was seen as a 'last resort' in at least one study (Jackson and Raftos, 1997).

Fear

Fear as a major factor discouraging whistleblowing was evident in 12 out of the 17 studies reviewed. Participants' most common fear was of personal repercussions against themselves and their families (Jackson et al, 2010), but they also feared legal action being taken against them (Almutary and Lewis, 2012; Uribe et al., 2002) or being blamed for involvement in the wrongdoing (Chiang and Pepper, 2006). As well as acting as a disincentive to whistleblowing, fear also had a significant impact upon staff wellbeing, leading to anxiety and sickness absences (Jackson et al, 2010) and often staff were denied time off for stress (Calcraft, 2007). A nurse in Attree's (2007) study reported first hand experiences of backlash, backstabbing and isolation following

raising concerns whilst another had experienced negative social outcomes such as isolation and a withdrawal of social support. These were perceived as an indication of peer disapproval of whistleblowing.

The experiences of nurses in Attree's (2007) and Black's (2011) study highlights that fear is also a systemic factor as it is created by the way in which organisations respond to whistleblowing. Fear was a subjective feeling with an objective basis. Whistleblowers in Jackson's (2010) study spoke of a 'climate of fear' which permeated the culture of the organisation, leading them to feel unsafe in their working environment (see *systemic factors*).

Diverse responses to wrongdoing

There is often a dichotomy assumed in whistleblowing research suggesting that the only choice that exists to an individual is between whistleblowing or remaining silent. In reality individuals employ a range of diverse responses to wrongdoing. Participants in Jones and Kelly's (2014) study indicated that they would prefer to raise concerns in a team meeting rather than through a whistleblowing process. They reported that their response would depend on the severity of the incident and they would contact senior members of staff or an external agency when there was physical harm to a patient. In situations perceived to be less serious they preferred to raise the matter directly with colleagues, use their status as a learner to curiously question colleagues, bring the patient into the conversation or to use humour. There was an overwhelming preference for verbal rather than written reporting.

Participants in Jackson and Raftos' (1997) study also indicated that they had whistleblown as a 'last resort' when concerns were not being listened to, suggesting they preferred to use other methods first.

Table 1. Summary of included studies.

Author(s) Date Country	Focus	Study type	Participants (n)	Data/measures used	Key findings	Quality rating
Ahern and McDonald (2001) Australia	Differences in beliefs between nurse whistleblowers and 'non reporters'	Quantitative	95 Registered nurses	Questionnaire consisting of a mixture of patient advocacy and 'traditional role' statements, rated on a likert scale and questionnaire on whistleblowing experiences	Whistleblowers more likely to support beliefs about patient advocacy, non-reporters more likely to support beliefs about the traditional role of nursing eg. Following doctor's orders.	75%
Almutary and Lewis (2012) Saudi Arabia	Frequency of reporting of medication errors in Saudi Arabia and factors that contribute to non-reporting.	Quantitative	62 registered nurses	Questionnaire asking about demographic variables, perceptions of reporting and barriers.	Fear of repercussion and lawsuits as well as administration factors were associated with likelihood of reporting.	50%
Attree (2007) England	Factors affecting nurses' decisions to raise concerns about standards of practice.	Qualitative	142 nurses	Semi structured interviews within grounded theory framework.	Fear of repercussions, retribution, labelling and blame were disincentives to raising concerns. Reporting was perceived as a high-risk; low benefit action. Nurses lacked confidence in reporting systems.	75%
Black (2011) Nevada, United States	Nurses' experiences of workplace attitudes towards patient advocacy activities.	Quantitative	564 active nurses	The Registered Nurses' Workplace Support for Patient Advocacy Activities Study questionnaire. Questions about patient advocacy and perceived ability to report.	Those who didn't report were worried about retaliation, felt nothing would come of the report, didn't know who to report to or didn't think it was their concern.	50%
Calcraft (2007) England	Current whistleblowing practice across the UK	Qualitative	Care staff: 15 took part in interviews and an unspecified number in focus groups	Interviews and focus groups	Themes: support for whistleblowers, feedback for whistleblowers, impact on working relationships, organisational culture and power, recognising and challenging abuse, closed teams and powerful individuals, negative views of whistleblowing and management and organisational culture.	75%
Chiang, Lin, Hsu and Ma	Factors predicting failure to report medical administration	Quantitative	872 nurses providing direct	Subscales of the Chinese version of the Nursing	The top predictors of underreporting were experience of making MAEs	100%

(2010) Taiwan	errors.		care.	Practice environment Scale (C-NPES), The 18 item Chinese version of the Nurse's Reporting Barriers questionnaire (C-NRB), demographic questionnaire and questions about experience of reporting.	and having the same attitude towards reporting self and other MAEs. Fear, nursing quality, professional development and reporting rate were also predictors.	
Chiang and Pepper (2006) Taiwan	Potential barriers to medical administration error reporting and associations with cultural factors, nursing environment and demographic characteristics.	Quantitative	597 nurses in a medical centre in Taiwan.	The 'Reason why MAEs are not reported' questionnaire (Wakefield, 1996), The Chinese version of the index of Hierarchy of Authority (Hsieh, 1998) and the face-concern scale (Chiang) and the work environment questionnaire (Blegen et al, 2004).	The major perceived barrier was fear. The next strongest perceived barriers were administrative barriers e.g management attitudes towards MAES, not receiving feedback and too much emphasis on MAE as a quality indicator of care.	75%
Davis and Konishi (2007) Japan	The meaning and experience of whistleblowing.	Mixed methods	24 Japanese nurses, masters' students and clinical teachers at a nursing college in Japan.	A questionnaire about patient advocacy, which included a session on whistleblowing. It contained open ended and forced choice questions.	Reasons for whistleblowing were concern about harm to the patient and the belief the head nurse should know what goes on in the hospitals. Reasons for not whistleblowing were it was better to deal with it informally, poor outcome from reporting and subjectivity of perceived wrongdoing.	25%
Goldie, Schwartz, McConnachie and Morrison, (2003) Scotland	Students' attitudes and potential behaviour in relation to whistleblowing as they pass through the medical curriculum.	Mixed methods	Cohort sample of 162 medical students followed over 5 year course.	The adapted Ethics in Health Care Survey Instrument (EHCI), specifically the whistleblowing vignette.	There was no significant movement towards consensus at any point during the curriculum. Thinking was not always consistent with the consensus of the profession and non-consensus responses were most often categorised as relating to the student's personal values/morality.	75%
Jackson and Raftos (1997) Australia	The experience of nurse whistleblowers, factors that encouraged and dissuaded them.	Qualitative	Three registered nurses in a residential care institution,	Interviews conducted over several weeks, within feminist approach.	Participants went through three phases in the whistleblowing process: trepidation and optimism, barriers and obstacles and disillusionment and defeat.	100%
Jackson et al (2010) Australia	The experience of whistleblowing and reasons behind the decision to blow the whistle.	Qualitative	11 nurses.	Interviews.	Themes: reasons for whistleblowing: I just couldn't advocate, feeling silenced: nobody speaks out and climate of fear: you are just not safe.	75%
Jones and Kelly (2014)	Staff's perceptions of whistleblowing as well as	Qualitative	60 health and social care employees.	Interviews and focus groups.	Whistleblowing was perceived negatively and considered risky.	75%

Wales.	other strategies that may be used to raise concerns.				Local solutions were preferred and drew upon personal than regulatory ethics to shape responses.	
King (2001) Midwest United States	Perceptions of intentional and unintentional wrongdoing and how this influences decisions about what to do about questionable behaviour.	Quantitative	372 registered nurses	Anonymous survey consisting of five intentional and five unintentional items.	Intentional and unintentional wrongdoings were perceived significantly differently and perception of intentionality was related to questionable behaviour.	75%
Kingston, Evans, Smith and Berry, 2004 Australia	Attitudes of medical and nursing staff towards reporting incidents and near misses	Qualitative	33 nurses in doctors	Focus groups.	Themes: habit, intention (social factors, affect and perceived consequences), motivation and facilitating conditions.	75%
Moore & McAuliffe, 2010 Ireland	Perceptions of reporters and non-reporters, elucidating factors that prevent reporting.	Quantitative	152 nurses working in acute hospitals.	Questionnaires adapted from a tool used to evaluate the experience attitudes of nurses, doctors and GPs to reporting poor care in the UK.	Non reporters cited 'not wanting to cause trouble' and 'not being sure if it's the right thing to do' as reasons for their reluctance to report. 'Fear of retribution' was the most common reason given by non-reporters for failing to report.	75%
Ohnishi, Hayama, Asai and Kosugi, 2008 Japan	Understanding the process of whistleblowing	Qualitative	Two nurses.	Interview within grounded theory framework.	Stages: suspicion of wrongdoing, awareness of wrongdoing, driving force to continue to work, firm conviction, after whistleblowing: wavering emotions, stable emotions.	75%
Uribe, Schweikhart, Pathak and Marsh, 2002 Midwest United States	Perceived barriers to medical error reporting and perceived ability to modify these.	Mixed methods	Nine professionals in the initial nominal group, 122 completed the resulting survey.	Nominal group session to identify potential barriers and enhancers to reporting, questionnaire based on these factors.	Six factors acted as barriers: time involved in documenting errors, extra work, process not anonymous, thinking it's unnecessary to report as there was no negative outcome, fear of lawsuits and not wanting to 'tell on' someone else. The easiest to modify were related to the process and hardest to the culture.	50%

Systemic Factors

Relationships with colleagues

In some studies, participants discussed the influence of workplace relationships upon decisions to raise concerns. In teams where the relationship between staff was close and there were a few powerful individuals it was harder for new staff members to form good relationships with the team. This made it harder to challenge staff and led to complacency and poor practice (Calcraft, 2007). Chiang and Pepper (2006) found an interplay between relationships with colleagues and the wider culture. In their study 54.6% of barriers to raising concerns were accounted for by power hierarchy, face-saving concern and work environment factors. They concluded that aspects of traditional Chinese culture such as respect for authority and the desire to maintain harmonious relationships may have contributed to face-saving concern being a barrier to reporting and may create an ethical dilemma for staff who witness poor care between their loyalty to the patient and to the staff group. This was also highlighted by Ohnishi et al. (2008) whose participants continued to work after noticing poor practice out of a sense of duty.

Organisational Culture

Organisational culture refers to the unspoken rules that govern how an organisation operates and how members relate to one another. Participants in Jones and Kelly's (2013) study described how workplace norms evolved over time and became habitual so that the abnormal became normal, it 'just crept in'. There was no conscious intention to permit unethical behaviour or low standards of care but this happened incrementally over time. This could also be reinforced by long serving members of staff who developed ways of doing things which were then passed on to new staff observing them. This led to unethical behaviour going unnoticed and therefore less likelihood of it being reported.

In Jackson et al's (2010) study participants described a 'culture of silence' in which it was not easy for individuals to speak up when they had concerns. They felt that the

systems they worked in conspired to create this which deterred them from reporting. Kingston et al. (2004) found that the organisation was seen as blaming and punitive and lacking the resources to adequately support whistleblowers. Calcraft (2007) highlighted that within the same organisation there may be conflicting rules and norms for what constitutes acceptable behaviour, creating uncertainty about when to whistleblow. Despite the existence of policies supporting whistleblowing, unwritten rules and norms construed raising concerns as 'not the done thing' (Attree, 2007). A culture in which reporting concerns entails a lengthy administrative process was also a deterrent (Black, 2011).

Feedback

A contributing factor to whistleblowing being seen as a 'high risk-low benefit' endeavour (Attree, 2007) was the lack of feedback given to staff about the outcome of their report, leading them to feel as though reporting had made no difference. This was highly likely to deter them from whistleblowing in the future. Not receiving feedback or thinking nothing had come of the report was highlighted as a disincentive to reporting in four out of 17 studies (Chiang and Pepper, 2006; Black, 2011; Calcraft, 2007; Davis and Konishi, 2007). Whilst there may be a limit to what information can be shared with whistleblowers, Calcraft (2007) suggested it is important to at least provide the outcome of the report to facilitate closure.

Quality assessment

Possible scores on the MMAT range from 0 (poor quality) to 100 % (high quality). The papers included in this review obtained scores of 25% (n=1), 50% (n=3), 75% (n=11) and 100% (n=2) respectively, demonstrating a range of quality from somewhat poor to high. Most of the studies included in the study were deemed to be of good or high quality (see Appendix D). No studies were excluded from the review, as it was not deemed that findings were significantly affected by areas of poor quality. The main area that appeared to be overlooked by qualitative studies was reflexivity as researchers did not (with one exception) explain how their personal values,

assumptions and interactions with participants may have influenced the research. This is an important aspect of qualitative research, which must be taken into consideration when assessing the generalisability of the findings. Quantitative studies suffered from low response rates, possibly reflecting the sensitivity and confidential nature of the subject matter.

Discussion

This review explored the psychological and systemic factors influencing whistleblowing decisions in healthcare. Psychological factors were grouped into individual beliefs about advocacy and professional roles, fear and diverse responses to wrongdoing. Systemic factors were categorised as relationships with colleagues, organisational culture and feedback. These highlighted that individuals do not take the decision to whistleblow in isolation and that individual experiences such as fear can permeate an organisation. It was therefore not always possible to categorise variables as either individual or systemic.

The literature on whistleblowing in healthcare consists of quantitative, qualitative and mixed methods studies across various settings. Studies were generally of medium to high quality. However research usually involved nurses and may not apply to other professional groups. Quantitative research suffered from a poor response rate, which may be because of fear in coming forward. Qualitative researchers in this area have generally not reported on reflexivity. Many of the studies reviewed were conducted in countries other than the United Kingdom, therefore some of the findings identified may not be applicable to NHS contexts. For example Chiang and Pepper (2006) discussed how traditional Chinese beliefs in the importance of group harmony may contribute to an increased sense of not wanting to whistleblow on colleagues. Having said this, a greater number of factors seemed to be universal such as fear, administrative barriers and feeling nothing would come of reporting. Finally, many findings related to responses on hypothetical scenarios and may not reflect how people would actually make decisions given a 'live' situation.

The identification of fear as a major disincentive to whistleblowing was unsurprising given the stressful and isolating process described in the Freedom to Speak up Report (Francis, 2015). The findings of this review support the findings of the report that whistleblowers experience blame within the organisation, negative connotations are attached to the term 'whistleblowing' and many do not receive feedback on the outcome of their report. Such an aversive experience is unlikely to encourage others to come forward in the future.

Similarly to the findings of literature on whistleblowing in business settings (Sims and Keenan, 1998; Brennan and Kelly, 2007; Keil et al., 2010), staff in healthcare were influenced by the ease of the reporting process and cultural factors. However healthcare workers were also influenced by their perception of their role. For many this facilitated whistleblowing as they held beliefs about patient advocacy but others were more concerned with deference to the hierarchy of nurse to doctor. Healthcare staff who held patient advocacy beliefs were liable to find themselves in an ethical dilemma when these beliefs conflicted with those of the organisation.

The findings of this review can be understood in terms of their impact upon the decision making process at the different stages of Rest's (1986) framework for ethical decision making. Moral sensitivity was influenced by staff training, the level of ambiguity in the situation and the extent to which poor care practices had become the norm in a particular organisation. Moral judgement was influenced largely by personal values rather than professional consensus. The majority of the factors identified by this review appeared to influence the moral intention phase. These included fear of consequences, beliefs about professional role, organisational culture and not wanting to harm relationships with colleagues, as well as previous experiences of the outcome of reporting.The latter could be likened to Jones' (1991) concept of probability of effect.

There are numerous implications for healthcare organisations in terms of how to facilitate whistleblowing and safe, high quality patient care. Some of the factors identified by the literature may be easier to modify than others. For example it may be

possible to reduce the amount of time it takes staff to report concerns, provide training as to the acceptable standards of care and provide other, more informal, means of raising concerns for those who prefer not to go through the whistleblowing process. Furthermore it seems feasible to employ a system whereby whistleblowers can be notified as to the general outcome of their report, or demonstrate how incident reporting has contributed to patient care using specific examples.

To achieve these changes requires motivation on the part of organisations. Where this is not present and the organisational culture is one of fear, blame, punishment and close knit- relationships between small numbers of powerful staff it will be much more difficult to achieve change. In these cases external help may be required and there should be impartial agencies on hand to support the whistleblower. This is the idea behind 'whistleblower guardians' in the NHS (Francis, 2015).

In the longer term, policy designed to protect whistleblowers is likely to be ineffective without change to organisational culture. Ultimately the aim should be to create the kind of transparent, supportive culture in which concerns can be raised before they get to the whistleblowing stage. The literature on compassionate organisations may indicate a way forward in this regard.

This review also provides directions and areas for future research, namely the effectiveness of interventions aimed at removing some of the barriers to whistleblowing. It would also be useful to conduct research with other staff groups not currently included in the body of literature, in order to enrich our understanding of the influence of the perception of professional role and training upon the decision to whistleblow.

Conclusion

This review adds to knowledge of whistleblowing in healthcare by illuminating some of the psychological and systemic factors that influence staff decisions to whistleblow. The literature on this topic is generally of high quality, but is limited by the use of hypothetical scenarios, lack of representation of a range of professions and low response rates which reduce its generalisability. Nevertheless the review suggests

important implications for clinical practice, such as the need to address issues of organisational culture. Finally, further research concerning the effectiveness of interventions to facilitate whistleblowing and with different staff groups is indicated.

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Part Two: Empirical Paper

Families' experiences of raising concerns in healthcare services: An interpretative phenomenological analysis.

This paper is written in the format ready for submission to the Journal of Applied Research in Intellectual Disabilities.

See Appendix E. for author guidelines.

Word count: 5709

Abstract

Background This study aimed to increase understanding of the lived experiences of families of people with intellectual disabilities when noticing and raising concerns in services. A qualitative design was employed. ***Methods*** Seven participants were recruited through local and national voluntary agencies; five were mothers of people with intellectual disabilities, one was the aunt and one the sister. Participants took part in semi structured interviews centred on their experiences of noticing and raising concerns, these were recorded and transcribed. The data was analysed using Interpretative Phenomenological Analysis (IPA; Smith, 1996). ***Results*** The data was grouped into three overarching themes: relationships between staff, family and service user, the nature and importance of concerns and the process of raising concerns. ***Conclusions*** This research highlights important implications for services such as the need to simplify the process of raising concerns, attend to the relationship with families and ensure advocacy services are available for those without family.

Keywords: Adult safeguarding, residential care, family, intellectual disabilities

Background

Abuse of vulnerable adults in residential settings has come into public awareness in recent times due to a number of high profile cases such as Winterbourne View (see Department of Health, 2012b for response) and Mid Staffordshire Hospitals. These cases led the government to publish the Francis Report (Francis, 2013) detailing areas for improvement, which included a greater emphasis on prevention rather than reactive measures. In order to prevent abuse happening, it is essential to understand the factors underlying it.

Research has identified a number of societal, organisational and individual factors that may increase the potential for abuse to occur. Whilst the social model of disability (Oliver, 1983) was highly influential, some criticised the model for not sufficiently acknowledging impairment (see Shakespeare and Watson, 2001; Lang, 2001; Dewsbury et al., 2004). Oliver (2013) argues that this renewed emphasis on impairment has led to a reduction in support for disabled people who are now classified according to the 'severity of their need' and that barriers are now largely being ignored as disability has become localised within the individual once again. Related to this, societal discourses can contribute to a culture in which the potential for abuse of vulnerable people is fostered. Campbell (2008) discussed the concept of 'ableism' that permeates our society. Through this lens 'able bodied' is equated with normal and therefore anything that deviates from this is considered abnormal and viewed negatively. As a consequence oppression and violence become part of the lives of many disabled people (Goodley and Runswick-Cole, 2011).

Within organisations, risk factors for abuse include high workloads, staff burnout, poor multidisciplinary teamwork, conflict between staff and clients and staff stress (Reader and Gillespie, 2013). In addition, measures brought in with the aim of ensuring good quality care can have unintended consequences. For example targets brought in by the government may have been successful at reducing waiting times (The King's Fund, 2010) but may have had the unforeseen consequences of creating a culture of 'box

ticking' in which meeting targets becomes the main priority at the expense of actual patient care and lead to the sort of falsifications seen at Mid Staffordshire Hospitals (Bidgood, 2013). Burns, Hyde and Killet (2013) described institutional abuse using the 'wicked problem' analogy. This refers to a problem which is complex and where attempted solutions may have the unintended consequence of themselves creating new problems.

At an individual level, individuals with certain characteristics or belonging to a particular group may be at high risk of becoming victims of abuse than others. Beadle-Brown et al. (2010) found that, unlike other groups, the incidence of abuse of people with intellectual disabilities had actually increased between 1998 and 2005 and they were more likely to have experienced sexual abuse but less likely to have experienced financial abuse or neglect than those without an intellectual disability. People living in residential care settings were more likely to be victims of abuse (particularly if they were placed out of area) which was most often perpetrated by another service user. Other individual characteristics that can place someone at higher risk of abuse include physical frailty, sensory impairment, 'challenging behaviour', communication problems and institutionalisation (Jenkins and Davis, 2011).

There is growing recognition that involving service users, carers, family and friends in decisions about care can help to ensure care quality. The government report 'No decision about me without me' (Department of Health, 2012a) highlighted the need for the provision of good quality information to enable people to take part in decision making and for the information to be available in accessible formats. Indeed this is particularly important for people with intellectual disabilities as they are often disempowered and encouraged to rely on others. Participatory Action Research aims to involve service users in designing and carrying out research. Such research has suggested that some service users are unclear as to what constitutes abuse and that they may feel more inclined to report their concerns when supported by a family member (Bennett et al, 2013). Furthermore as isolation is considered to be an

important factor that increases the likelihood of a service becoming abusive, it may be that someone outside of the service would be more likely to notice when something is wrong (White et al., 2003). Despite this, no literature could be identified which explored families' views on and experiences of residential care services, particularly when they had concerns. Although 'grey' literature exists in the form of blogs and social media campaigns by family members; there were no empirical studies which might enable this information to be disseminated more widely. The current study aimed to address this gap in the literature by investigating the lived experience of families and carers of noticing and reporting concerns in services. The study aimed to provide families with an opportunity to share their experiences with the aim of influencing safeguarding practices in residential care settings.

Method
Sampling and recruitment
Seven family members of people with intellectual disabilities took part in the study. All were female, five were the mother of someone with an intellectual disability, and one was the aunt and one the sister. Participants ranged in age from 20 to 86 years old and were educated to at least degree level. All of their relatives lived in residential care, supported living or attended respite care and all participants had experience of noticing concerns in services. Opportunity sampling was used to recruit participants from local and national voluntary agencies (see Table 1 for participant details).

Table 1. Participant demographic information

Pseudonym	Gender	Age	Relationship to person in residential care
Jenny	Female	58	Mother
Sophie	Female	52	Mother
Maggie	Female	51	Mother

Vicky	Female	44	Mother
Barbara	Female	64	Mother
Rosie	Female	20	Sister
Amy	Female	86	Aunt

Interviews and analysis

Ethical approval for the study was obtained from the University of Hull Faculty of Health and Social Care Research Ethics Committee (see Appendix F for letter of ethical approval).

Emails were sent round to members of local voluntary agencies by the heads of those agencies with information about the study (see Appendix G for information sheet) and family members agreed for their contact details to be passed on to the researcher. They were then contacted by the lead researcher and offered the opportunity to ask questions about the information they had read before deciding whether to take part. If participants consented to take part a semi structured interview was arranged at a time and place convenient for them (usually their home). At the beginning of the interview itself, participants were again given the opportunity to discuss the study with the researcher and ask questions and they signed a written consent form (Appendix H). All participants expressed concern about the confidentiality of the study so the researcher reassured them by discussing procedure for safe storage and anonymization of the data and offered to share the written themes of the study for them to check they were satisfied with the level of confidentiality. Participants also completed a demographic information questionnaire (Appendix I), which allowed the researcher to collect information about the composition of the sample. These were stored separately to participant data.

The interviews ranged in length from 28 minutes to 1 hour 41 minutes, following a semi structured interview schedule (Appendix J) and were recorded using a Dictaphone. This allowed for the recordings to be transcribed to facilitate data analysis, at which

point the original recordings were destroyed. When transcribing the interviews every effort was made to ensure anonymity by removing names and other potentially identifying information.

Interpretative phenomenological analysis (IPA; Smith, 1996) was used to analyse the data as the emphasis of this study was on understanding the lived experiences of relatives of people with intellectual disabilities in relation to noticing and raising concerns in services. Analysis was an inductive and iterative process which was undertaken in line with the guidelines outlined by Smith, Flowers and Larkin (2009). Firstly transcripts were examined in detail, thorough notes were made (see Appendix K for worked example) and emergent patterns identified within individual transcripts and subsequently across transcripts. To enhance credibility a record was kept of all decisions taken during analysis and the transcripts were independently coded by the second researcher and other members of the research team who then came together to compare findings and discuss and refine emergent themes.

Findings
The interviewee's accounts were grouped into three overarching themes, within these overarching themes several subthemes were identified (see Table 2).

Table 2. Summary of superordinate and subordinate themes.

Superordinate theme	Subordinate themes
RELATIONSHIPS BETWEEN FAMILY, STAFF AND SERVICE USER	Management
	Trust and Mistrust
	Communication and Information Sharing
THE NATURE AND IMPORTANCE OF CONCERNS	'The little things'
	Understanding the person in their context
THE PROCESS OF RAISING CONCERNS	Responsiveness
	The process itself
	How it feels

Relationships between family, staff and service user

Trust and mistrust

All of the participants spoke at length about their families' relationship with staff and services. These relationships appeared to be characterised by high levels of mistrust and misconceptions. Three participants expressed doubts about staff's ability to notice and report the things that families were concerned about:

 "*I sometimes wonder, erm, if I was dead who would do the things that I do?*" (Jenny).

Mistrust was further evident in that on some occasions when concerns were reported participants felt that staff had tried to cover up what was going on, and that they had not been kept informed because staff were trying to work out what to tell them.

"*I really do feel….*they're *trying to get their story together and they're covering themselves".* (Maggie)

Despite encountering difficulties relating to staff, participants acknowledged that staff had a difficult job and gave examples of times when staff had exceeded their expectations. They sought to maintain a positive relationship with staff by also providing positive feedback.

Communication and information sharing

All participants talked about the importance of open and honest communication between staff and families at all times but especially when there were concerns. Participants recalled experiences where this did not happen and they had found it very difficult to find out information about what was happening to their relative. Participants indicated that they would prefer to have regular updates from staff and to be asked if there was anything staff were unsure about. Participants described how they sought to make themselves available to answer staff's questions and to encourage a dialogue. However they did not always find that this was reciprocated by staff. They reported that they were not always kept informed, questions were not answered and how this led to them trying different ways to get the information:

"*I thought right ok I'm going to have to go and get somebody to- a private investigator*"

(Sophie)*.*

This was exacerbated by finding that adequate documentation was not kept in some occasions, such that sometimes participants never found out the full extent of what had happened. This lack of communication increased the mistrust families felt towards staff, as one family member said:

'*You can forgive human error or mistakes if you're kept informed but when things are hidden that's when you get suspicious'.* (Maggie)

Management

The relationship with management was viewed as particularly important. Participants described times when they had had no faith in managers. They valued a direct channel of communication with a manager who was responsive to concerns. Some participants felt that the manager determined the culture of the team:

"*If they get good professionals that are at the top....somebody told me...that everybody's frightened of [manager] and I thought good because that means she keeps them on their toes." (*Amy*)*

However others had experienced that good management was not always sufficient to ensure good quality care. In some cases, good intentions were not everything and despite good leadership this did not seem to filter down to other levels of care:

"*I think the current manager is doing her very level best....but the staff don't use them [communication tools]"* (Jenny)

The Nature and Importance of Concerns

The nature of participants' concerns was grouped into two subthemes: 'The little things' and 'understanding the person in their context'.

'The little things'

All of the participants recounted that their current concerns were not about serious incidents of abuse but about smaller issues relating to care, which were described as 'silly little things', 'niggles' and 'hiccups':

"It was always something that was kind of like niggling a little bit but …it wasn't a massive issue really" (Rosie)

Examples of these were relatives coming home wearing a different service users' clothes, community activities not being facilitated and concerns about their relatives' sleeping patterns and diet. Their concerns often seemed to arise because of a mismatch between how the participants would look after their relative at home and how they were looked after in a residential care setting and because of the impact on the resident's dignity and quality of life. Participants indicated if they had a serious concern about abuse they would have no hesitation about acting on this immediately:

'If it's something that's dangerous then I'll always pursue it" (Barbara)

However the small things were also very important to them:

'They're the details of life that are important' (Jenny).

One participant expressed the view that:

'If you deal with the small stuff it won't become big stuff' (Maggie).

Understanding the person in their context

Many of the concerns that participants had seemed to arise because of a perceived lack of understanding of the service user and their context. Family members were keen to stress that although their relative no longer lived at home, this did not mean that families stopped being involved in their lives. Issues to do with care still had an effect on the whole family. One participant said of staff:

"They need to see us as a whole family, they need to see us as a whole entity and that [relative] is who he is because he's got a past" (Maggie)

Family members' knowledge of their relative made it more likely that they would be able to notice changes in their behaviour that might indicate that they were unhappy, when they were unable to communicate this verbally. There was potential for caring to conflict with other demands placed upon the family (such as work) and to cause conflict with other family members at times. This sometimes led to feelings of guilt and anxiety, particularly among the older participants who expressed concern about what would happen to their relatives when they were no longer around to advocate for them. Participants' suggested that their response to concerns was influenced by their own personality, values and by their past experiences. Vicky explained how culture effects how abuse is perceived and dealt with by families and the support received from communities:

"*They think….because your child's disabled you've done something wrong in your past life….and nobody wants to know*" (Vicky)

One participant spoke about how her family had worked with staff to help them understand how their past experiences shaped current reactions

"…*done speaking for them as well about growing up and the problems we've had and why we behave the way we do*" (Maggie)

One participant talked about feeling a sense of 'solidarity' and community with other families in the same situation and another participant thought it would be useful for families to have more opportunities to come together to discuss care, and that this could then help those who were less confident to be able to raise concerns.

The process of raising concerns

Several subthemes related to the process families went through once concerns had been noticed and raised. These are described below.

The process itself

The process of raising concerns was described as frustrating and lengthy, requiring a lot of effort, confidence, assertiveness and persistence on the part of the family

member. Some family members found the process easier to navigate than others, having had experience through work of similar reporting systems. Participants stated that it was helpful to have straightforward and informal ways of giving feedback, for example through links provided in emails and that formal complaints procedures might deter people from reporting the smaller things:

"I just think the complaints procedure is just so…it makes it so formal, it makes it so adversarial, that I would much rather have a conversation with somebody than to get into a position where we're opposing each other". (Barbara)

They also suggested that it could be made easier by families having a contact person so they know who to raise concerns with and having more clarity on their rights to support throughout this process.

"…just make it clear what help can be offered and erm make that information, spread that information as widely as possible" (Rosie).

Some participants gained support from talking to other families using services:

"…and then you meet the families of other people there as well so there's quite- I think there's quite like a support network there definitely" (Rosie)

Others rarely had contact with other families and reported feeling suspicious when services did not want families to talk to each other. Others preferred to act alone or turn to other sources of support such as social media:

"I spoke to a lot of other people…disabled people who had had the experience, erm national campaigners, national solicitors…" (Barbara)

Participants also spoke of their role as communicating on behalf of their relative who would find it difficult to communicate themselves if they had concerns. The process itself was not accessible to people with intellectual disabilities, particularly those who could not communicate verbally. Behaviour that was in fact indicative of distress was often dismissed as 'puberty' or a person being difficult and was recognised as a form of

reporting only by the family member. Vicky's experience was that when incidents were taken further, legal processes were also not accessible to people who could not communicate verbally, which mean the cases were ultimately dropped:

"*It lost its momentum and er the Police said they can't prosecute because they haven't got sufficient evidence, the fact that [relative] can't talk…but that's the last thing they should be saying. They should be trusting his behaviour".* (Vicky)

Responsiveness

Participants recalled that the response they received when they raised concerns was not always satisfactory. In one case the manager was not available to discuss the concern and in others there was a perceived lack of response to concerns, with families not given a definitive outcome or response. Other times they met with defensiveness from staff or found that their concerns were minimised or even not believed:

"*They would say yeah everything's fine…so I was kind of reassured to some extent but was aware that things weren't as they should be*'" (Sophie).

Two other participants remarked that staff sometimes took the raising of concerns personally or were perceived to overreact and that this resulted in them feeling they had to be careful how they worded things and even deterred them from reporting:

"*That kind of overreaction makes you think twice the next time you want to raise something because you don't want people to get fired or disciplined or-you just want them to put it right."* (Barbara)

How it feels

Participants described being in a state of constant worry and uncertainty about when the next concern would arise, as one participant said:

"*It doesn't mean you can rest on your laurels, ever, ever" (*Maggie*).*

There was a sense of constant vigilance and heightened awareness towards concerns and strong emotions when incidents did happen:

"*…you get so angry and you feel like a failure because you've allowed it to happen although you weren't even there. But it's your child, you're meant to protect your child.*" (Vicky)

Participants had noticed and worried about other service users who did not have family and questioned who was available to advocate on their behalf:

"*I'm afraid there's quite a few things that go on with people that haven't got anybody*" (Amy).

Family members were cautious of being perceived as 'fussy', 'a nuisance' and 'bolshy' for raising concerns:

"*…they'd just brush it under the carpet and say yeah alright, goodbye, your child can leave now and they don't want to deal with the troublesome family.*" (Vicky)

They were careful in how they brought up concerns with staff:

"*It's that, as a parent, I feel that….you've got to have a certain amount of erm tact and diplomacy…*" (Maggie)

It was evident that fears of the potential consequences of raising a concern often mediated participants' responses to 'the little things'. Four of the participants reported that families would need to be certain that there would be no repercussions on their relative of raising something:

"*You're thinking well is she going to get, are they going to be nasty to her because we've reported them…*" (Amy)

Others were concerned about the possibility of the local authority deeming their relative's placement to be unsuitable If they raised too many issues with it, particularly as they perceived that these placements were relatively expensive and the local

authority were concerned about money. Participants were aware that services were under pressure and there was a lack of resources and desire to save money. Participants acknowledged that, although they had some concerns, the current placements were very good and they did not want their relative to have to move to somewhere else where they would be unsure of the quality of care they would receive:

"*It's better the devil you know*" (Jenny)

It was notable that all the participants expressed worries about whether the information disclosed in their interview would be kept confidential, worried about whether their relative could be identified by the use of particular examples and requested copies of the resulting transcripts. This may have been related to the fear of possible repercussions from talking about negative experiences of care.

Participants used phrases like '*a hell of a battle*' and '*fighting game*' to describe the process they went through when they had concerns. One participant summarised this by saying:

"*You have to fight for everything*" (Sophie).

Participants reflected on how their response to concerns had been shaped by their experiences:

"I thought ok how come they're getting more than I am and then I started observing and I realised she was shouting and I ended up learning to shout and he who shouts the loudest gets the services." (Vicky)

There was often a sense that they had to escalate concerns before anything would be done about it and that sometimes this required going to quite extreme lengths to feel heard. For example one participant spoke about threatening to get the Police and a private investigator involved to find out what was happening to her relative. Only at this point did the service become responsive to her concerns:

"I said well if you don't inform me I'll get the Police involved …I need to get to the bottom of this…and then they became a bit more helpful" (Sophie).

Whilst '*How it feels' was* written up as a subtheme of the superordinate theme '*The process of raising concerns';* it could be applied across all of the superordinate themes as there was a strong emotional component throughout participants' accounts. For example in the *'Relationships between family, staff and service user'* theme participants were fearful of how they were perceived and of staff not picking up on concerns. In the *'Nature and importance of concerns'* theme participants experienced guilt when their relative was treated poorly.

Discussion
This study aimed to fill a gap in the existing literature on the prevention of abuse of vulnerable adults by exploring families' experiences of noticing and raising concerns in residential services looking after their relative. Findings were grouped into three overarching themes: relationships between staff, family and service user, the nature and importance of concerns and the process of raising concerns. However the subtheme of 'how It feels' was evident across all the superordinate themes, suggesting it is important to attend to and understand the emotional experience of families. It was evident that relationships were very important to families and were often complicated to navigate. Relationships between staff and families appeared to be often characterised by high levels of mistrust and misconceptions, leading to withholding of information which in turn perpetuated this cycle. Likewise the reporting process was described as highly stressful and requiring a great deal of persistence on the part of the family member. A somewhat more surprising finding related to the nature of concerns that families had; as these were often about smaller aspects of day to day care rather than serious incidents of abuse (although examples of the latter were also described). Participants stated that they knew what to do about abuse and had no hesitation in acting and were largely satisfied with the services, but it was these details of everyday life that were often more complicated to address.

The families in these studies described experiences that were consistent with findings from previous research into the prevention of abuse (Beadle-Brown et al, 2010; Reader and Gillespie, 2013). Their relatives often had communication problems which made it difficult for them to raise concerns themselves and meant they required another person to advocate on their behalf as the reporting process was not accessible to individuals with intellectual disabilities. Families were concerned about the implications of this when they themselves were no longer around or for those who did not have family. This raised a question over what family members do when they notice concerns relating to another resident who is not their relative. Organisational factors such as high staff turnover were regularly encountered, which has implications given the central importance of developing good relationships between services and families.

There appeared to be similarities between the processes families go through when raising concerns and the process staff go through to whistleblow, therefore some common lessons can be learned here. These included the fear of repercussions (either on oneself in the case of staff or on one's relative in the case of families; Jackson et al.,2010), a lack of responsiveness to concerns (Chiang and Pepper, 2006; Black, 2011; Calcraft, 2007; Davis and Konishi, 2007), the importance of relationship (be these with colleagues or between staff and families (Calcraft, 2007) and the relative ease of the process for reporting (Black, 2011).

This study was the first to examine in detail the experience of families relating to services and noticing and reporting concerns. A key strength was the IPA methodology which allowed for an in depth exploration of this phenomena. However a limitations of this study was that the sample was very homogenous in terms of gender and educational experience and it is likely that people choosing to participate in a study such as this would already be highly involved in service user advocacy activities and may be more knowledgeable than others about safeguarding processes. It would be helpful seek the views of a more diverse range of family to determine whether these

views are shared. This would help inform services as to how best to support as many families as possible.

There are many clinical implications arising from this study. Services need to recognise that individuals exist in their family context and work more closely to foster relationships with family. There was evidence that families tried to encourage dialogue with staff by making themselves available but that they did not always feel that this was reciprocated by staff. It was helpful to have a single contact person with whom to communicate (such as a manager or keyworker) and to receive regular updates about their relative's care. This open communication would help to reduce mistrust and make it easier for staff and families to raise concerns. Involving families in training and recruiting staff could help to increase understanding and empathy for each other. Participants in this study suggested that reporting processes could be made easier by having online facilities for example, using the families' preferred method of communication and encouraging families to get together to support each other to raise concerns. More efforts need to be made to involve people with different communication needs in this process and to recognise that behaviour may be a form of reporting. Families need to be informed as to the procedures for raising concerns about any service user; regardless of whether this person is their relative or not. Finally, service users who do not have family regularly visiting them need to have an independent advocate who can notice and raise concerns on their behalf.

As the first study in this area, it has many implications for future research which could further understanding speaking to families of people in other types of support settings; such as those receiving services in their own home or attending day services. The initial findings of this study are intended to inspire future researchers to consider families' perspectives more, in particular to discover more about the nature of the relationship between families and services, as this was found to be of crucial importance. This study also suggests that more research should focus on the smaller aspects of day to day care that make up service users' quality of life as these are more

difficult to know how to manage than those serious incidences of abuse. Services could make use of tools such as the Early Indicators of Concern (Marsland, Oakes and White, 2007) which facilitates decision making based upon these smaller aspects of the care environment.

This study was significant as it was the first to explore the experience of families in relation to noticing and raising concerns in services, therefore beginning to address a gap in the current literature and identifying ways forward in ensuring higher quality residential care. Families were keen to tell their stories and have a wealth of experience that can and should be harnessed in the quest to help services develop their safeguarding procedures, with the overall aim of protecting vulnerable adults who use these services from abuse and poor care and improving quality of life for them and their families.

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Part Three: Appendices

Appendix A- Author guidelines: Journal of Adult Protection

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Article Length

Articles should be between 4000 and 6000 words in length. This includes all text including references and appendices. Please allow 350 words for each figure or table.

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ll contributing authors' names should be added to the ScholarOne submission, and their names arranged in the correct order for publication.

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Research funding

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Structured Abstract

Authors must supply a structured abstract in their submission, set out under 4-7 sub-headings (see our "How to... write an abstract" guide for practical help and guidance):

Purpose (mandatory)

Design/methodology/approach (mandatory)

Findings (mandatory)

Research limitations/implications (if applicable)

Practical implications (if applicable)

Social implications (if applicable)

Originality/value (mandatory)

Maximum is 250 words in total (including keywords and article classification, see below).

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Headings must be concise, with a clear indication of the distinction between the hierarchy of headings.

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Figures created in MS Word, MS PowerPoint, MS Excel, Illustrator should be supplied in their native formats. Electronic figures created in other applications should be copied

from the origination software and pasted into a blank MS Word document or saved and imported into an MS Word document or alternatively create a .pdf file from the origination software.

Figures which cannot be supplied as above are acceptable in the standard image formats which are: .pdf, .ai, and .eps. If you are unable to supply graphics in these formats then please ensure they are .tif, .jpeg, or .bmp at a resolution of at least 300dpi and at least 10cm wide.

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e.g. Harrow, R. (2005), No Place to Hide, Simon & Schuster, New York, NY.

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e.g. Calabrese, F.A. (2005), "The early pathways: theory to practice – a continuum", in Stankosky, M. (Ed.), Creating the Discipline of Knowledge Management, Elsevier, New York, NY, pp. 15-20.

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e.g. Aumueller, D. (2005), "Semantic authoring and retrieval within a wiki", paper presented at the European Semantic Web Conference (ESWC), 29 May-1 June, Heraklion, Crete, available at: http://dbs.uni-leipzig.de/file/aumueller05wiksar.pdf (accessed 20 February 2007).

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e.g. Encyclopaedia Britannica (1926) "Psychology of culture contact", Vol. 1, 13th ed., Encyclopaedia Britannica, London and New York, NY, pp. 765-71.

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e.g. Litman, S. (1902), "Mechanism & Technique of Commerce", Unpublished Manuscript, Simon Litman Papers, Record series 9/5/29 Box 3, University of Illinois Archives, Urbana-Champaign, IL.

For electronic sources   If available online, the full URL should be supplied at the end of the reference, as well as a date that the resource was accessed.

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Appendix B- Data extraction forms

Qualitative studies (NICE, 2008)

Heading	Subheading		For completion by reviewer(s)
	Bibliographic details		Journal article √ Report Website Book Book Chapter
	Name of reviewer	*Circle*	Reviewer 1 Reviewer 2 Reviewer 3
	Eligible?		Yes√ No Unclear
	Reviewer's rating	*As matrix*	
	Typology	*Review? Primary Research? Case studies or descriptive accounts?*	Primary Research
	Participants	*Evidence from service users, carers, policy or practitioner*	
	Study aims	*What were the study's aims and purpose?*	
	Key findings	*What are the key study findings?*	
	Evaluative summary	*Draw together brief comments on the study as a whole and its strengths and weaknesses. Is further*	

		work required? What are its implications for policy, practice and theory? If any?	
	Service users' and carers' perspective	*Does the study report on the experience of service users? Does the study report on the experience of carers? How were they involved in the study (design, dissemination etc.)?*	
Ethical standards		*Was ethical committee approval obtained? Was informed consent obtained? Does the study address ethical issues adequately? Has confidentiality been maintained?*	
Context	Aims	*Are the aims and purpose of the study clearly stated?*	Yes no unclear
Setting	Area and care setting	*What is the geographical and care setting for the study?*	Urban rural semi-urban semi-rural mixed
	Rationale	*What is the rationale and*	

		appropriaten ess for this choice?	
	Detail	*Is there sufficient detail about the setting?*	Yes no unclear
	Timing	*Over what period did the data collection take place?*	
Sample	Inclusion criteria	*Who was included in the study?*	
	Exclusion criteria	*Who was excluded from the study?*	
	Selection	*How was the sample selected? Were there any factors that influenced how the sample was selected (e.g. access, timescale issues?)*	
	Size	*What is the size of the sample and groups comprising the study?*	
	Appropriateness	*Is the sample appropriate in terms of its ability to meet the aims of the study, the depth of data that it enables to be collected and its breadth?*	Yes no unclear
Data collection	Methods	*What data collection methods*	Interview Focus group observation mixed methods

		were used? Was the data collection adequately described and rigorously conducted?	Yes √ no unclear
	Role of researcher	*What is the role of the researcher within the setting? Are there any potential conflicts of interest?*	
	Fieldwork	*Is the process of fieldwork adequately described?*	
	Data analysis	*How are the data analysed? How adequate is the description of the data analysis? Is adequate evidence provided to support the analysis (e.g. use of original data, iterative analysis, efforts to establish validity and reliability)? Is the study set in context in terms of findings and relevant theory?*	
	Researcher's potential bias	*Are the researcher's/ researchers' own positon,*	

		assumptions and possible biases outlined? Indicate how they could affect the study in terms of analysis and interpretation of the data.	
	Reflexivity	*Are the findings substantiated by the data and has consideration been given to any limitations of the methods or data that may have affected the results?*	Yes no unclear
Outcomes	Outcomes	*What outcome measures were adopted? What was the impact of the study for (a) service users (b) carers (c) practitioners (d) organisation responsible for service*	
Findings	Themes		
	Conclusions		
	Opinions	*What this person argues*	
Policy and practice	Generalisability	*To what extent are the study*	

		findings generalizable? What is the country of study? How applicable are the study findings to the system in the UK? Are the conclusions justified?	

Quantitative Studies

Heading	Subheading	For completion by reviewer(s)
Bibliographic details	*Citation*	
	Type of publication	Journal article.
Name of reviewer		
Participant group	*Inclusion criteria Exclusion criteria Selection Size Appropriateness*	
Study aims		
Setting	*Area and care setting Rationale for choice Sufficient detail of setting? Timing (over what period did data collection take place?)*	
Data collection	*Methods Potential conflicts of interest?*	
Data analysis	*How were the data analysed? How appropriate was this?*	
Key findings		
Conclusions		
Implications for policy and practice		
Evaluative summary	*Describe overall strengths and weaknesses of the study*	
Service user and/or carer involvement?		

Ethical standards	*Ethical approval obtained?* *Ethical issues discussed?*	

Mixed methods studies

Heading	Subheading	For completion by reviewer(s)
Bibliographic details	*Citation*	
	Type of publication	Journal article.
Name of reviewer		Naomi Bright
Participant group	*Inclusion criteria* *Exclusion criteria* *Selection* *Size* *Appropriateness*	
Study aims		
Setting	*Area and care setting* *Rationale for choice* *Sufficient detail of setting?* *Timing (over what period did data collection take place?)*	
Data collection	*Methods* *Potential conflicts of interest?*	
Data analysis	*How were the data analysed?* *How appropriate was this?*	
Key findings		
Conclusions		
Implications for policy and practice		
Evaluative summary	*Describe overall strengths and weaknesses of the study*	
Service user and/or carer involvement?		
Ethical standards	*Ethical approval obtained?* *Ethical issues discussed?*	
Reflexivity and Researcher's potential bias		

Appendix C- Mixed Methods Appraisal Tool
(MMAT; Pluye, Gagnon, Griffiths & Johnson-Lafleur, 2009)

Types of mixed methods study components or primary studies	Methodological quality criteria **Appraisal for**	Responses (score 1 if present, 0 if not present)		
		Yes tell	**No Comments**	**Can't**
Screening questions (for all types)	• Are there clear qualitative and quantitative research questions (or objectives) or a clear mixed-methods research question (or objective)? • Do the collected data allow address the research question (objective)? E.g. consider whether the follow up period is long enough for the outcome to occur (for longitudinal studies or study components. *Further appraisal may not be feasible or appropriate where the answer is 'No' or 'Can't tell' to one or both screening questions.*			
1. Qualitative	1.1 Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)? 1.2 Is the process for analysing qualitative data relevant to address the research question (objective)? 1.3 Is appropriate consideration given to how findings relate to the context e.g. the setting in which the data were collected? 1.4 Is appropriate consideration given to how findings relate to researchers' influence e.g. through their interactions with participants?			
2. Quantitative randomised control trials	2.1 Is there a clear description of the randomisation (or an appropriate sequence generation)? 2.2 Is there a clear description of the allocation concealment (or blinding when applicable)? 2.3 Are there complete outcome data (80% or above)? 2.4 Is there low withdrawal/drop out (below 20%)?			
3. Quantitative non randomised	3.1 Are participants (organisations) recruited In a way that minimises selection bias? 3.2 Are measurements appropriate (clear origin, or validity known, or standard instrument and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes? 3.3 In the groups being compared (exposed vs none exposed; with intervention vs without; cases vs controls) are the participants comparable, or do the researchers take into account (control for) the differences between these groups?			

	3.4 Are there complete outcome data (80% or above) and, when applicable, an acceptable response rate (60% or above), or an acceptable follow up rate for cohort studies (depending on the duration of the follow up)?	
4. Quantitative descriptive	4.1 Is the sampling strategy relevant to address the quantitative research questions (quantitative aspect of the mixed methods question)? 4.2 Is the sample representative of the population under study? 4.3 Are measurements appropriate (clear origin, validity known or standard instrument)? 4.4 Is there an acceptable response rate (60% or above)?	
5. Mixed methods	5.1 Is the mixed methods design relevant to address the qualitative and quantitative research questions (objectives) or the qualitative and quantitative aspects of the mixed methods research question (objective)? 5.2 Is the integration of qualitative and quantitative data (results) relevant to address the research question (objective)? 5.3 Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results) in a triangulation design? *Criteria for the qualitative component (1.1 to 1.4) and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4 or 4.1 to 4.4) must also be applied.*	

Appendix D- Table of quality assessment scores

Study	Qualitative				Quantitative RCT				Quantitative Non-randomised				Quantitative Descriptive				Mixed Methods			Score
	1.1	1.2	1.3	1.4	2.1	2.2	2.3	2.4	3.1	3.2	3.3	3.4	4.1	4.2	4.3	4.4	5.1	5.2	5.3	
Ahern & McDonald, 2002	-	-	-	-	-	-	-	-	-	-	-	-	1	1	1	0	-	-	-	75%
Almutary & Lewis, 2012	-	-	-	-	-	-	-	-	-	-	-	-	1	0	1	0	-	-	-	50%
Atree, 2007	1	1	1	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	75%
Black, 2011	-	-	-	-	-	-	-	-	-	-	-	-	1	1	0	0	-	-	-	50%
Calcraft, 2007	1	1	1	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	75%
Chiang, Lin, Hsu & Ma, 2010	-	-	-	-	-	-	-	-	-	-	-	-	1	1	1	1	-	-	-	100%
Chiang & Pepper, 2006	-	-	-	-	-	-	-	-	-	-	-	-	1	0	1	1	-	-	-	75%
Davis & Konishi, 2007	1	1	1	0	-	-	-	-	-	-	-	-	1	0	0	0	1	1	0	25%*
Goldie, Schwartz, McConnachie & Morrison, 2003	1	1	1	0	-	-	-	-	-	-	-	-	1	1	1	0	1	1	0	75%
Jackson & Raftos, 1997	1	1	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	100%
Jackson et al, 2010	1	1	1	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	75%
Jones & Kelly, 2014	1	1	1	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	75%
King, 2001	1	1	1	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	75%
Kingston, Evans, Smith & Berry, 2004	1	1	1	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	75%
Moore & McAuliffe, 2010	-	-	-	-	-	-	-	-	-	-	-	-	1	1	1	0	-	-	-	75%
Onishi, Hayama, Asai & Kosugi, 2008	1	1	1	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	75%
Uribe, Schweikhart, Pathak & Marsh, 2002	1	1	0	0	-	-	-	-	-	-	-	-	1	1	1	0	1	1	0	50%

* Mixed methods studies are assigned the lowest score obtained from the relevant areas of methodology.

Appendix E: Author guidelines - Journal of Applied Research in Intellectual Disabilities

Author Guidelines

Crosscheck

The journal to which you are submitting your manuscript employs a plagiarism detection system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.

1. GENERAL

The Journal of Applied Research in Intellectual Disabilities is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

Please read the instructions below carefully for details on submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to visit http://authorservices.wiley.com/bauthor/ for further information on the preparation and submission of articles.

All manuscripts must be submitted solely to this journal and not published, in press, or submitted elsewhere.

2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

2.1 Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

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

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

2.2 Ethical Approvals

Research involving human participants will only be pubished if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included.

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

Ethics of investigation: Papers not in agreement with the guidelines of the Helsinki Declaration as revised in 1975 will not be accepted for publication.

2.3 Clinical Trials

Clinical trials should be reported using the CONSORT guidelines available at www.consort-statement.org. A CONSORT checklist should also be included in the submission material (www.consort-statement.org).

The Journal of Applied Research in Intellectual Disabilities encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: www.clinicaltrials.org, www.isrctn.org. The clinical trial registration number and name of the trial register will then be published with the paper.

2.4 Conflict of Interest and Source of Funding

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

The Journal of Applied Research in Intellectual Disabilities requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflict of interest noted. As of 1st March 2007, this information is a requirement for all manuscripts submitted to the journal and will be published in a highlighted box on the title page of the article. Please include this information under the separate headings of 'Source of Funding' and 'Conflict of Interest' at the end of the manuscript.

If the author does not include a conflict of interest statement in the manuscript, then the following statement will be included by default: 'No conflict of interest has been declared'.

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4. SUBMISSION OF MANUSCRIPTS

Submissions are now made online using ScholarOne Manuscripts (formerly Manuscript Central). To submit to the journal go to http:// mc.manuscriptcentral.com/jarid. If this is the first time you have used the system you will be asked to register by clicking on 'create an account'. Full instructions on making your submission are provided. You should receive an acknowledgement within a few minutes. Thereafter, the system will keep you informed of the process of your submission through refereeing, any revisions that are required and a final decision.

4.1 Manuscript Files Accepted

Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rft) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing.

To allow double-blinded review, please upload your manuscript and title page as **separate** files.

Please upload:
1. Your manuscript without title page under the file designation 'main document'.
2. Figure files under the file designation 'figures'.
3. Title page which should include title, authors (including corresponding author contact details), acknowledgements and conflict of interest statement where applicable, should be uploaded under the file designation 'title page'.

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5. MANUSCRIPT TYPES ACCEPTED

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

6. MANUSCRIPT FORMAT AND STRUCTURE

6.1 Format

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

6.2 Structure

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

Cover Page: A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.
Running Title: A short title of not more than fifty characters, including spaces, should be provided.
Keywords: Up to six key words to aid indexing should also be provided.
Main Text: All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. Authors should make use of headings within the main paper as follows: Introduction, Method, Results and Discussion. Subheadings can be used as appropriate. All authors must clearly state their research questions, aims or hypotheses clearly at the end of the Introduction. Figures and Tables should be submitted as a separate file.
Style: Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:
-Include all figure legends, and tables with their legends if available.
-Do not use the carriage return (enter) at the end of lines within a paragraph.
-Turn the hyphenation option off.
-In the cover email, specify any special characters used to represent non-keyboard characters.
-Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).
-Use a tab, not spaces, to separate data points in tables.
-If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

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

6.3 References

The reference list should be in alphabetic order thus:
-Emerson E. (1995) Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities. Cambridge University Press, Cambridge.

-McGill P. & Toogood A. (1993) Organising community placements. In: Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.
-Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. Mental Handicap Research 5, 130-145

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

We recommend the use of a tool such as EndNote or Reference Manager for reference management and formatting.
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Reference Manager reference styles can be searched for here: http://www.refman.com/support/rmstyles.asp

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6.4 Tables, Figures and Figure Legends

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

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

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

Further information can be obtained at Wiley-Blackwell's guidelines for figures:http://authorservices.wiley.com/bauthor/illustration.asp.

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The corresponding author will receive an e-mail alert containing a link to a website. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF file from this site.

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Appendix F-Letter of Ethical Approval

(Removed for hard binding)

UNIVERSITY OF Hull

Information about the Research

Title of the study: Understanding the experience of families and carers when noticing and reporting concerns in services.

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please read this information carefully and ask us if you have any questions.

What is the purpose of the study?

We are interested in family and carers' experiences of noticing worrying things or having a feeling that 'something is wrong' in a service caring for their relative or friend who has an intellectual disability. You may have seen on the news in recent years stories of abuse in services that are meant to be caring for people. Research has shown us that there are a number of factors which come together to create the sort of environment where people are abused. Lots of this research has been done about services for people with learning disabilities. This research has been helpful in pointing out 'warning signs' to look out for in services. We are interested in what you have found helpful in making decisions about reporting concerns and what has made it difficult. We hope that by understanding your experiences better we will be able to help families going through this in future. This will help us all work towards a goal of helping to keep people with learning disabilities safe from harm in services.

Why have I been invited?

This information has been given to people who have a relative or friend who has a learning disability and who lives in a residential service (including supported living). We are looking for people who have had experience of having concerns about a service and deciding whether to report it. You have been given the information because you may meet this criteria and may be interested in taking part in our study.

Do I have to take part?

No, it is completely up to you whether or not you want to take part in the study. Although your relative will not be identifiable in any part of the write up you may want to talk with them before deciding whether to take part. If after reading this information you are interested in taking part please fill out the contact details form and send it back in the freepost envelope provided. The researcher will then contact you to check you still want to take part and answer any questions you may have. You will be asked to sign a consent form to say you have agreed to take part. You are free to withdraw from the study up until the point where data analysis begins (the researcher will tell you when this will be). You don't have to give a reason if you decide to withdraw and it won't affect any services you or your friend or relative receive.

What will happen if I take part?

If you agree to take part please fill in the contact details form and send it back in the freepost envelope. The researcher will then contact you to answer any questions you may have and arrange a time to come and talk to you about your experiences. This will be arranged at a place that is convenient for you (as far

as possible), for example at one of the charity services you attend. The researcher will ask you about your experiences of noticing concerns in services and how you decided whether or not to report them. This is expected to take between 1 and 2 hours. The conversation will be audio recorded if you agree to this.

What are the possible disadvantages and risks of taking part?
The study will take 1-2 hours of your time, which may be inconvenient for you, and you may have to travel a short distance to meet the researcher. The topics we will be discussing are sensitive and you may experience some emotional distress as a result. The researcher will help you with this during the session and other members of staff at the charity will be able to help you access further support if it is needed afterwards. During the conversation concerns about services might come up that need to be reported. The sessions are not primarily for this purpose but the researcher will be able to help you talk through your options. If you decide together that the concerns need to be reported the researcher can do this for you. It will not be your responsibility to report it. The researcher will ask you for details of what your concerns are and will discuss this with her supervisor. If necessary they will then report it to the local safeguarding adults board, who are responsible for investigating.

What are the possible benefits of taking part?
We cannot promise that you will have any direct benefits from taking part in the study, although some people do find it helpful to talk about their experiences, even if this can be upsetting. We hope that the information we get from this study will help other families who are going through similar experiences as you have had and will help us to ensure that people with learning disabilities are safer from abuse in the services they use.

What will happen if I decide I no longer wish to take part?
You are free to withdraw from the study before the results are analysed and the study is written up; you do not have to give a reason to withdraw. Any information collected about you will be destroyed. This will not affect any services you or your friend or relative receive.

What if there is a problem?
If any problems arise for you during the research or you have any concerns about the study you can talk to the researcher or their supervisor who will do their best to answer any questions.

Will my taking part in the study be kept confidential?
Yes any information you provide to us will be kept confidential. Your recordings and notes on these will be stored securely and will assigned a participant code to protect your identity. Identifying information will not be used in the final write up of the study. The only exception to this will be if you tell us something which indicates to us that you or somebody else might be at risk of harm, in which case we are obliged to tell people to make sure everyone is kept safe. We will always try to discuss this with you first.

What will happen to the results of the study?
After all the information has been collected it will be analysed and written up for publication in a scientific journal and submitted as a doctoral thesis to the University of Hull. You will not be identifiable in any written report. If you wish to have a short written summary of the results or access to the published article the researcher can provide this.

Who is organising and funding the research?

The research is being done as part of a doctoral programme in Clinical Psychology. The research is organised and funded by the University of Hull. Some sections of data collected during the study may be looked at by people from the University of Hull or from regulatory authorities to ensure that the researcher followed the proper guidance.

<u>Who has reviewed the study?</u>
The study has been reviewed by an independent group of people whose job it is to ensure that the interests of participants are protected. This study has been given a favourable review by the University of Hull's Faculty of Health and Social Care Research Ethics Committee.
If you have any further questions or more information please contact Naomi Bright. Thank you for taking the time to read this information.
Yours sincerely,
Naomi Bright, Trainee Clinical Psychologist
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Appendix H- Consent form

UNIVERSITY OF Hull

Participant Identification Number:

CONSENT FORM

Title of project: **Understanding the experience of families and carers of noticing and reporting concerns in services.**

Name of researcher: **Naomi Bright.**

Please initial the box

1. I confirm that I have read and understood the information sheet dated 22/02/15 (version 1.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time up to data analysis, without giving any reason, without my medical care or legal rights being affected.

3. I consent to audio recordings and understand that these will be stored anonymously.

4. I agree to take part in the above study.

5. I understand that the results of this study will be written up for publication but that I will not be identified in any reports.

6. I agree/do not agree for my quotes to be used in the final report (delete as appropriate).

Name of participant   Date   Signature

_____   _____   _____

Name of person taking consent   Date   Signature

Appendix I- Participant demographics questionnaire

UNIVERSITY OF **Hull**

<u>Participant characteristics sheet</u>

This sheet asks some questions about you. Collecting this information helps us to understand how the findings of our study might have been influenced by participants' backgrounds. The data you share with us will not be used to personally identify you and will not be shared with anyone else.

If you prefer not to answer these questions please tick this box

1. How old are you in years?
   …………………………………………………………………………………
   ….

2. What is your gender?
   …………………………………………………………………………………
   …..

3. What is your ethnicity? Please tick one.

   ☐ White   ☐ Asian
   ☐ Black   ☐ Chinese
   ☐ Other (please state):

4. Highest level of education:

   ☐ no formal qualifications
   ☐ age 16 (e.g. GCSEs)
   ☐ age 16-18 (e.g. AS/A-levels)
   ☐ diploma
   ☐ degree
   ☐ post-graduate qualification

5. Employment (tick one):
   ☐ Employed
   ☐ Voluntary work

   ☐ Homemaker

   ☐ Unemployed

6. What is your relationship to the person living in residential care?
   ☐Father
   ☐Mother
   ☐Sister
   ☐Brother

☐Friend
Other (please state):

7. What kind of residential care service do they live in?
☐Registered care home
☐Supported living accommodation
☐Other (please state):
……………………………………………………………………

Appendix J- Semi structured interview schedule

This is a study exploring the experience of families and carers of noticing and reporting concerns they have about services. As such I am going to ask you some questions about these issues, but we can talk about whatever is important to you on this topic.

Deciding that something is of concern

1. Please give me an example of a time you noticed a concern in a service used by your friend or relative. What was it that you noticed?
   -Prompt until they describe the situation fully. Nb. If there is more than one time then   be sure to follow them all up throughout the interview.

2. How did you decide whether this was a concern? What was it about this that concerned you? How did you feel about the situation? What did you think about the situation at the time?

What happens next?

3. Please describe what happened after you noticed the concern. What happened next?
4. Did you talk to anyone about what you had noticed? Who did you speak to? How did you decide who to speak to? Who would you speak to first? If you did, what was the outcome of this?
5. If they did report it ask: who did you report it to? What was this process like? What happened?
6. What influenced your decision of what to do next?
   -Prompts: other people, beliefs, the process

   Facilitators
7. What things help someone to report concerns?
   -prompt: other people, ease/clarity of the process, organisational factors, individual/psychological factors, anticipated consequences

Obstacles

8. What things make it difficult to report something you are worried about?
   -prompt: as Q6.

Support

9. What do you think would make it easier to decide what to do in future? For people to report things that worry them? What would you like to happen to help people with these decisions?
10. What would you like professionals to do to help you if you had to make decisions like this again?

Other

11. Is there anything we haven't talked about on this topic that you think might be important for me to know?

Appendix K- Worked example of data analysis.

Emergent themes	Maggie (lines 1-63)	Comments
	Researcher (R): Great, so can you give me an example of a time that you noticed a concern in a service that was used by your relative and what was it that you noticed?	
	Maggie (M): Erm…the most concern we've ever had was when [name] was in a residential school	
	R: right	
	M: And he was about 14, 15	
	R: mhm	*Have to know the person well to be able to tell when something is wrong- behaviour as a communication.*
	M: he's 24 now, but he was 14 or 15 at the time and, erm, <u>he's non-verbal and he has severe autism, severe learning disability so erm you have to watch his behaviour</u>	
	R: yes	
	M: to gauge how he's feeling and erm over a period of home visits we noticed that he was having up to four or five hours a day of incidents. <u>So it was really increasing and we knew something was seriously wrong and he was unhappy </u>and then when we would drive back to the school on Sunday evening to take- he wouldn't get out of the car.	*Had a feeling something was wrong.*
	R: right	
Concerns were minimised.	M: and they'd take two or three staff to come out to try and help to get him out of the car and <u>when I was asking 'well why is he so unwilling to come back in? I'm really worried about this', you know, 'it makes me feel awful bringing him back when he's exhibiting this type</u>	*Concerns minimised-staff tried to reassure.*

Nagging doubt	of behaviour' and they said 'oh it's just puberty, we've seen it with some of the other young people here, obviously they would prefer to be at home, it's all part and parcel of puberty you know and there's nothing to worry about'.	
	R: right	
	M: And so you've got a nagging doubt in your mind but you kind of think 'well, they've been through this before, they know what they're talking about, this is the first time I've experienced it. So your guts are telling you one thing and your head is telling you another.	*Kind of a gut feeling or intuition.*
	R: yeah	
	M: And erm it was getting to the point where it was becoming unmanageable to bring [name] home, so that even on the journey back he would be in a really distressed state and he'd be kicking the back of the chair and flailing about and opening the windows, kicking his shoes off, throwing his-and this is coming down the motorway, it was a two and a half hour journey.	*Sounds distressing for the family as well as unsafe.*
	R: mm, gosh.	*Effect of this on family?*
	M: To get to and from the school because it was in [different county] and erm, the journey became unsafe.	
	R: yeah	
Trying different ways to get the information. .	M: And so, I was doing that journey on my own so we had to get an escort then and then once he was home he still didn't settle and he always used to love coming home for a weekend but he still wasn't settling.	
	R: yeah	*Not taken seriously or given much information from*
	M: So, kept questioning it further with different members of staff, so you know go to a different	

	member of staff to the one you've asked before and you're getting similar kinds of answers or non-committal answers, it's not really being resolved. R: right M: and <u>I was on the parents' committee so I started asking the head of service</u>, you know 'I'm really concerned'- '<u>oh it's just puberty, when one starts they all start' and 'one will start the other one off' and 'of course he'd rather be at home, he's just letting you know about it' and 'he's bigger and stronger now'</u>, you know, this kind of answer. <u>Didn't really get any kind of answers and this went on for a good 18 months</u>	*staff, lack of resolution.* *Used position to get information. Concerns minimised, behaviour not recognised as a form of reporting.*

Appendix L- Epistemological statement

This statement presents a reflection on the epistemological stance taken by the researcher towards this field, assumptions brought to the research and the rationale for the chosen research methodology. Ontological stances concern our perspectives on knowledge and give way to epistemological stances concerning the best way to acquire knowledge. These stances shape how research is carried out.

The researcher took a *relativist* ontological stance which is characterised by the absence of 'absolute thinking' (Rössler & Matsuno, 1998). Relativist ontology assumes that reality as we know it is subjectively constructed by each individual through their experiences and interactions with others (Cohen & Crabtree, 2006). This distinguishes it from a *positivist* stance which assumes there is a single truth or understanding which can become known through a process of experimentation and observation (Ryan, 2006). The researcher also took an *interpretivist* viewpoint, believing that we cannot separate ourselves from what we know as who we are and our experiences and assumptions are inextricably linked to how we view the world and others, such that a particular phenomenon cannot be separated from ourselves and studied 'objectively' (Cohen & Crabtree, 2006). This therefore implies that the researcher's values influence all phases of the research process.

There was no existing literature on the experience of families of people with intellectual disabilities when noticing and reporting concerns in services, therefore the researcher was not overly influenced by previous knowledge on this topic. However on a personal level they assumed that the experiences would be highly stressful. The researcher was familiar with systemic models of thinking and with issues of power as this was a major focus of the clinical training course they were on. Therefore they were sensitive to these issues and posited that families may feel powerless in the system of residential care.

Qualitative and quantitative research differ in the epistemological positions they take, which in turns shapes the methods used. Quantitative research is underpinned by *positivist* epistemology and as such seeks to develop universal laws or theories of human behaviour based on systematic study of a particular 'reality'. Qualitative research is underpinned by *relativist* and *interpretivist* epistemology and is concerned with describing and understanding a particular phenomenon experienced by an individual and understanding the meaning for the individual (Yilmaz, 2013). Qualitative methodology was chosen for the current study as its epistemological position was suited to the aim of the research which was to understand the experience of families of people with intellectual disabilities when noticing and reporting concerns in services. As this was the first study into this area an exploratory approach was deemed appropriate.

Interpretative phenomenological analysis (IPA; Smith, 1996) was chosen over other qualitative methodologies because of its focus on understanding the detail of participants' personal experiences whilst recognising that access to this is limited by the researcher's own preconceptions. It allows for a more in depth analysis than thematic analysis which usually produces more superficial descriptions of commonalities between people's experiences. Grounded theory was rejected as this study did not aim to generate theory and the sample size would have been insufficient to do so, particularly considering the inevitable restraints on resources and time that come with a doctoral project.

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Appendix M- Reflective statement

I initially embarked upon this project with some trepidation as it was to be a much larger piece of research than any I had so far undertaken. I was unfamiliar with qualitative methodology as I had not conducted any qualitative research prior to doctoral training and during training had only completed a small service evaluation using thematic analysis. However I was also excited as the idea developed, I believed that my research was truly novel and addressed a gap in the current literature which would be important and which could really help make a difference to the lives of people with intellectual disabilities and their families.

My initial enthusiasm was short-lived as when I reached the recruitment phase I had no participants and time was ticking away. I was disappointed and wondered why families did not value the research as much as I had thought they would. I felt anxious as it seemed as though everyone else was much further ahead than myself. I tried to focus solely on my own research journey and not compare myself to others but this was difficult as research was understandably the main topic of conversation amongst other trainees and staff.

At this point I met regularly with my supervisor and other members of the research team to discuss my worries and we decided to submit a minor amendment to ethical approval to allow me to recruit from more organisations than originally stated. Making plans helped me to feel less anxious for a time, but the real breakthrough when we discovered a miscommunication leading to many family members not receiving the invitation to take part. To me this summed up perfectly two of the main challenges I faced throughout the thesis process: relying on other people and trying to communicate to others the importance of what you are doing. I wondered whether these experiences paralleled those of families when relating to services.

After that the participants started rolling in and the research was really on its way. I felt a sense of relief and it no longer seemed like an impossible task to finish the project. I

was more than happy to travel the hundreds of miles it took to interview some of the participants, and felt a huge sense of gratitude towards them for taking part. I was humbled by how openly they shared their (often deeply distressing) experiences with me, a total stranger. This renewed my motivation to complete the research to the best of my ability in order to do their accounts justice, however this also came with a huge sense of responsibility. There was a compromise to be made between analysing the data and writing it up as thoroughly as I would like and the time constraints which I was under with the deadline rapidly approaching.

In the end the deadline itself may have been something of a blessing in disguise, as it helped me learn to let go of a piece of work when its 'good enough' and without it I could likely have continued to write and write and the perfectionist in me would never have been satisfied with what was produced. I can only hope that the finished product does justice to my participants' stories and goes some way towards making sure that the difficult things they have experienced happen less often in the future. I chose to submit to two journals which are well known and publish similar studies in this field and where the word counts were not too limiting. I had many interesting discussions with my participants and family as to how best to disseminate the research more widely to maximise its impact, for example social media, blogs and to service managers. I hope to take these ideas forward.

I would encourage others undertaking a similar project in the future to maintain clear and regular channels of communication with all of the people involved in their research and to network as widely as possible as I think showing my face to organisations would've helped to ensure the research was prioritised. As difficult as it is, comparing yourself to others is rarely helpful as all projects are very different and everyone has their own struggles. Above all you need to be resilient and choose a supportive and experienced supervisor. Finally keep in mind the reasons why your research is important as this will sustain you through the challenging times.