

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

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Abstract

Background This exploratory study aimed to increase understanding of the experiences of families of people with intellectual disabilities when noticing and raising concerns in services. A qualitative design was employed. **Methods** Seven participants (all female) 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 analyzed using Interpretative Phenomenological Analysis (IPA; Smith, 1996). **Results** The data was grouped into three superordinate themes: the nature and importance of concerns, relationships between families and staff and the process of raising concerns. A key and surprising finding was the importance of 'the little things'. **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 identified 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 (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. The Health and Social Care Act 2014 imposed a statutory duty upon local authorities to investigate all suspicions of abuse or neglect towards a vulnerable adult in their area. In the year 2015-2016 102,970 safeguarding enquiries were opened by local authorities (Health and Social Care Information Centre, 2016). Individuals with learning disability related support needs made up the second highest number of enquiries. However these figures may actually underestimate the prevalence of abuse as they do not include enquires dealt with by partner agencies and not reported to councils.

Research has identified a number of societal, organisational and individual factors that may increase the potential for abuse to occur. Social models of disability draw a distinction between 'impairment' (an injury, illness or congenital condition) and 'disability' (a limitation of opportunities due to social and environmental barriers). A central principle of the social model of disability (Oliver, 1983) is that people are disabled not by their impairments but by the way they are isolated and excluded from society through a lack of suitable adaptations. The implication of this was that interventions designed to support people with a disability need to be targeted at the societal and not the individual level. Whilst the social model of disability (Oliver, 1983) was highly influential, some criticised the model for not sufficiently acknowledging impairment (Shakespeare and Watson, 2001; Lang, 2001; Dewsbury et al., 2004). Critics of the model viewed it as simplistic and socially deterministic and argued that impairment and disability cannot be separated from each other and that interventions should focus on the individual as well as societal level. 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). Organisational culture in underperforming care homes for people with severe intellectual disabilities may be characterised by 'misalignment of power holder values with the organisation's espoused values', a sense of 'otherness', an ethos of 'doing for not with', 'staff centred'-ness and 'resistance' to change (Bigby et al., 2012). 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) compared allegations of abuse towards people with and without an intellectual

disability. They found that the most common type of abuse amongst all groups was physical abuse. Sexual abuse was more prevalent in the intellectual disability sample.

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, literature is sparse regarding families' views on and experiences of residential care services, particularly when they have concerns. Although 'grey' literature exists in the form of blogs and social media campaigns by family members; there is a lack of empirical studies which might enable this information to be disseminated more widely. Most studies regarding reporting concerns related to staff experiences of whistleblowing and some of the issues facing them. These included the fear of repercussions (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 relationships (Calcraft, 2007) and the relative ease of the process for reporting (Black, 2011). However, a recent study by Ryan and Quinlan (2017) used focus groups to explore parental perceptions of communication and collaboration between themselves and health and education staff in the context of a reconfiguration of disability services in Ireland. They identified five principle themes. In the first theme of 'us versus them' participants reported that they often felt they were in a battle with professionals which caused them significant stress whilst trying to fulfil what they saw as their role to advocate for their child. Positive experiences were attributed to fortune. The second theme was 'lack of child/family centeredness', in this theme participants talked about feeling that their child was depersonalised by the system and left with a number of unmet needs. The third theme was 'lack of resources', with many parents attributing lack of services to lack of state funding. Theme four 'uncertain access to a complex system' described the difficulties in navigating a complex system in which the future was uncertain. The fifth theme was entitled 'keyworker' to summarise the parents' desire for the employment of a keyworker to act as a bridge between stakeholders, a secure base, an advisor and an advocate.

The current study aimed to build on the emerging literature by investigating the lived experience of families and carers specifically when 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.

Interviews and analysis

Ethical approval for the study was obtained from the University of Hull Faculty of Health and Social Care Research Ethics Committee.

Emails were sent round to members of local voluntary agencies by the heads of those agencies with information about the study 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 participants were again given the opportunity to discuss the study with the researcher and ask questions and they signed a written consent form. 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 which allowed the researcher to collect information about the composition of the sample. These were stored separately to interview data.

The interviews ranged in length from 28 minutes to 1 hour 41 minutes, following a semi structured interview schedule, beginning with an invitation for the participants to describe a situation in which they had noticed a concern in a service used by their friend or relative and what it was that they noticed. Depending on how much participants disclosed, this was followed up with more specific questions such as 'what happened next?', 'What influenced your decision about what to do?' Participants were then asked more generally about what they thought would help someone to report concerns and what makes it difficult and what they would like to happen to help people with these decisions in future. The interviews 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. IPA is a qualitative research approach which aims to explore in detail how people make sense of major experiences in their lives. IPA is committed to the detailed examination and comparison between a small number of cases, rather than seeking to make generalizable claims. Analysis was an inductive and iterative process which was undertaken in line with the guidelines outlined by Smith, Flowers and Larkin (2009). Paper based coding was used. According to Smith, Flowers and Larkin's guidelines firstly transcripts were examined in detail through reading and re-reading secondly initial notes were made on the transcripts to examine semantic content and language use. Thirdly emergent themes began to be identified within each individual transcript by summarising what was important in the various initial notes in a concise statement. The fourth step was to search for connections across the emergent themes within each transcript. This was achieved by typing up a list of the emergent themes, printing the list and cutting out the themes in order to practise rearranging them to indicate their proximity or distance from each other. The fifth step involved repeating the above process for each new transcript and the sixth and final stage was to look for patterns across the transcripts, which helps the analysis to move to a more theoretical level. 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 superordinate themes; within these superordinate themes several subordinate themes were identified. The superordinate themes were:

- The Nature and Importance of Concerns
- Relationships between family and staff
- The process of raising concerns

The Nature and Importance of Concerns

The nature of participants' concerns was grouped into subordinate themes: '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' (1.1.1). 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 (1.1.2). Examples of the more serious concerns that participants had encountered were inappropriate use of restraint and assault by another resident. However the small things were also very important to them (1.1.3) and participants felt that a willingness to address these made it less likely that more serious issues would arise (1.1.4).

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 family 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 (1.2.1).

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. Participants' suggested that their response to concerns was also influenced by their own personality, values and by their past experiences. Vicky explained how culture effects how abuse is perceived and can lead to stigma, which effects how it is dealt with by families and the support received from communities (1.2.2).

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.

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. One participant spoke about how her family had worked with staff, providing training to help them understand how their past experiences shaped current reactions (1.2.3).

Relationships between families and staff

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. Three participants expressed doubts about staff's ability to notice and report the things that families were concerned about (2.1.1) 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 (2.1.2).

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, such as keyworkers seeking out new activities they thought their relative might enjoy and going to a lot of effort to organise these. They sought to maintain a positive relationship with staff by also providing positive feedback (2.1.3). Positive examples of trust between staff and families were also noted (2.1.4).

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 by making staff aware that they could contact them at any time and providing multiple methods of contact, usually telephone and email. However they did not always find that this was reciprocated by staff. They reported that they were not always kept informed (2.2.1), questions were not answered and how this led to them trying different ways to get the information. 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 (2.2.2).

Some participants suggested that communication was made more of a challenge by having multiple parties involved, that is family members having communication with multiple staff. They indicated that they would prefer to have one person with whom to communicate their concerns (2.2.3).

Effective and trustworthy 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 (2.3.1):

Some participants felt that the manager determined the culture of the team: 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 (2.3.2):

The process of raising concerns

Several subordinate themes 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 (3.1.1).

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. This related again to building better relationships with staff, but was made more difficult by high levels of staff turnover.

Some participants gained support from talking to other families using services (3.1.2).

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 (3.1.3).

In addition to relatives, connections with other people who live at the service are important in the process of raising complaints. This is illustrated by a sense of conflict when participants had noticed and worried about other service users who did not have family and questioned who was available to advocate on their behalf (3.1.4).

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 (3.1.5).

Participants used phrases like '*a hell of a battle*' and '*fighting game*' to describe the process they went through when they had concerns (3.1.6). Participants reflected that their response to concerns had been shaped by their experiences (3.1.7).

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 (3.1.8).

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 (3.2.1)

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 (3.2.2).

How it feels

Participants described being in a state of constant worry and uncertainty about when the next concern would arise (3.3.1).

There was a sense of constant vigilance and heightened awareness towards concerns and strong emotions when incidents did happen (3.3.2).

Participants had noticed and worried about other service users who did not have family and questioned who was available to advocate on their behalf (3.3.3).

Family members were cautious of being perceived as 'fussy', 'a nuisance' and 'bolshy' for raising concerns (3.3.4).

As a result they were careful in how they brought up concerns with staff (3.3.5).

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 (3.3.6).

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 (3.3.7). 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.

Whilst '*How it feels*' was classified 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 families and staff*' 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: the nature and importance of concerns relationships between families and staff, 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. The theme of 'The relationship between staff, families and service user' appeared to correspond to that of 'us versus them' identified by Ryan and Quinlan (2017). 'The process of raising concerns' also identified problems with bureaucracy and 'box ticking'. 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 (Jackson et al., 2010; Chiang and Pepper, 2006;

Calcraft, 2007 & Davis and Konishi, 2007). 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 limitation of this study was that the sample of family carers was very homogenous in terms of gender (all female) and educational experience (all educated to at least degree level) 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 therefore be more knowledgeable than others about safeguarding processes. It would be helpful to seek the views of a more diverse range of relatives 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. For many families email was their preferred method of communication, which raises issues of confidentiality and information governance. It is important that families are informed that confidentiality of emails cannot be guaranteed and, depending on the organisation's policy, that emails may need to be recorded in client's files.

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 communicating concerns. 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 improve our understanding by 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, which is 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 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 facilitate decision making based upon these smaller aspects of the care environment. It would also be useful for researchers to focus on positive aspects of reporting and raising concerns, in order that we may learn from good practice. 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.

References

- Beadle Brown, J et al. (2010) Adult protection of people with ID: Incidence, nature and responses. *Journal of Applied Research in Intellectual Disabilities*, 23 (6), 575-584.
- Bennett, D., Flood, S., Howarth, J., Melsome, M. and Northway, R. (2013). Looking into Abuse: Research by People with Learning Disabilities. University of Glamorgan, Rhondda Cynon Taff People First and New Pathways.
- Bidgood, E. (2013). After Francis: Standards and Care Quality in the NHS. London: Civitas.
- Black, L.M. (2011). Tragedy into Policy: A Quantitative Study of Nurses' Attitudes Toward Patient Advocacy Activities. *American Journal of Nursing*, 111(6), 26-35.
- Burns, D., Hyde, P., and Killett, A. (2013). Wicked problems or wicked people? Reconceptualising institutional abuse. *Sociology of Health & Illness*, 35(4), 514--528.
- Calcraft, R. (2007). Blowing the whistle on abuse of adults with Learning Disabilities. *The Journal of Adult Protection*, 9(2), 15-29.
- Campbell, F.K. (2008). Refusing Able (ness): A Preliminary Conversation about Ableism. *A Journal of Media and Culture*, 11(3). <http://journal.media-culture.org.au/index.php/mcjournal/article/view/46>
- Chiang, H-Y., and Pepper, G.A. (2006). Barriers to Nurses' Reporting of Medication Administration Errors in Taiwan. *Journal of Nursing Scholarship*, 38(4), 392-399.
- Davis, A., J. and Konishi, E. (2007). Whistleblowing in Japan. *Nursing Ethics*, 14(2), 194-202.

Department of Health (2012a). *Liberating the NHS: No decision about me without me.*

London: Department of Health.

Department of Health (2012b). *Transforming care: A national response to Winterbourne*

View hospital. London: Department of Health.

Dewsbury, G., Clarke, K., Randall, D., Rouncefield, M., and Sommerville, I. (2004). The anti-social model of disability. *Disability & Society*, 19(2), 145-158.

Francis, R. (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Enquiry.*

London: The Stationary Office.

Goodley, D., and Runswick-Cole, K. (2011). The violence of disablism. *Sociology of Health and Illness*, 33(4), 1-16.

Health and Social Care Information Centre (2016). *Safeguarding Adults Annual Report, England 2015-16 Experimental Statistics.* Surrey: NHS Digital.

Jackson, D., Peters, K., Andrew, S., Edenborough, M., Halcomb, E., Luck, L., Salamonson, Y and Wilkes, L. (2010). Understanding whistleblowing: qualitative insights from nurse whistleblowers. *Journal of Advanced Nursing*, 66(10), 2194-201. doi: 10.1111/j.1365-2648.2010.05365.x. Epub 2010 Jul 2.

Jenkins R and Davies R (2011) Safeguarding people with learning disabilities *Learning Disability Practice* 14 (1) 32-39.

Lang, R. (2001). The development and critique of the social model of disability. *Unpublished Working Paper, Overseas Development Group, University of East Anglia.*
Retrieved, 2(20), 2014.

Marsland, D., Oakes, P., and White, C. (2007). Abuse in Care? The identification of early indicators of the abuse of people with learning disabilities in residential settings. *The Journal of Adult Protection* 9 (4) 6-20.

- Oliver, M. (1983). *Social Work with Disabled People*. Basingstoke: Macmillan.
- Oliver, M. (2013). The social model of disability: thirty years on. *Disability and Society*, 28(7), 1024-1026.
- Reader, T., and Gillespie, A. (2013). Patient neglect in healthcare institutions: a systematic review and conceptual model. *BMC Health Services Research*, 13(1), 156.
- Ryan, C., & Quinlan, E. (2017). Whoever shouts the loudest: Listening to parents of children with disabilities. *Journal of Applied Research in Intellectual Disabilities*, - 00, 1012
<https://doi.org/10.1111/jar.12354>
- Shakespeare, T., and Watson, N. (2001). The social model of disability: an outdated ideology? *Exploring theories and expanding methodologies: Where we are and where we need to go*, (2), 9-28. In Barnatt, S. and Altman, B. *Research in Social Science and Disability: volume 2 Exploring Theories and Expanding Methodologies*. London, Emerald.
- Smith, J.A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11(2), 261-271
- Smith J, Flowers P, and Larkin M (2009) *Interpretative Phenomenological Analysis: Theory, Method, Research*. London: Sage Publishing.
- The King's Fund (2010). Have targets improved NHS performance? Retrieved from <http://www.kingsfund.org.uk/projects/general-election-2010/key-election-questions/performance-targets>
- White, C., Holland, E., Marsland, D. and Oakes, P. (2003). The identification of environments and cultures that promote the abuse of people with intellectual disabilities: a review of the literature. *Journal of Applied Research in Intellectual Disabilities* 16 (1) 1-9.

TABLE 1. Representative quotes for ‘The Nature and Importance of Concerns’

1.1 The little things

- 1.1.1 It was always something that was kind of like niggling a little bit but ...it wasn't a massive issue really (Rosie)
- 1.1.2 If it's something that's dangerous then I'll always pursue it (Barbara)
- 1.1.3 They're the details of life that are important (Jenny)

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

1.2 Understanding the person in their context

1.2.1 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)

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

1.2.3 ...we (the family) have done speaking for them as well about growing up and the problems we've had and why we behave the way we do (Maggie)

TABLE 2. Representative quotes for 'Relationships between families and staff

2.1 Trust and mistrust

2.1.1 ...every time staff change you've always got that suspicion in the back of your mind- are they being completely honest with me? Are they going to tell me everything? (Maggie)

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

2.1.3 And erm, they send me surveys sometimes, err on- through emails or paper ones and I often- I always try and fill them in if I can because I know it's helpful, so saying positive things. (Sophie)

2.1.4 The key workers have always known a lot about [name] so I feel confident in their abilities. (Sophie)

2.2 Communication and information sharing

2.2.1 And you didn't always feel like there was much information-it was hard to get information (Sophie).

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

2.2.3 ...because the care staff turnover is so great that they don't always keep the same keyworker so sometimes you do feel that you haven't always got one person that you can actually go to (Sophie).

2.3 Effective and trustworthy management

2.3.1 I have email contact with the manager, I will email her about everything and anything I'm worried about. (Jenny)

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

TABLE 3. The process of raising concerns

3.1. The process itself

3.1.1 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)

3.1.2 ...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)

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

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

3.1.5 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)

3.1.6 You have to fight for everything (Sophie).

3.1.7 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)

3.1.8 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).

3.2 Responsiveness

3.2.1 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).

3.2.2 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)

3.3 How it feels

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

3.3.2 ...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)

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

3.3.4 ...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)

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

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

3.3.7 It's better the devil you know (Jenny)

