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**Intimate Care in the Lives of People with Severe and  
Profound Intellectual Disabilities: An ethnographic study  
using grounded theory within the theoretical  
framework of symbolic interactionism**

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**Julie Clark**

**A thesis submitted in partial fulfilment  
of the requirements of Thames Valley University  
for the degree of Doctor of Philosophy**

**July 2008**

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## **Dedication**

This thesis is dedicated to the people who participated in this study. I was privileged to be allowed access to the most private areas of their lives, and recognition for any impact this work has on the lives of others is owed to them.

## Abstract

This thesis explores the nature of intimate care interactions between people with severe and profound intellectual disabilities and the staff who work with them, within a theoretical framework of symbolic interactionism. The majority of people with severe and profound intellectual disabilities rely on others to meet their needs for intimate care on a daily basis and this area of care is therefore likely to contribute to their quality of life. However, intimate care has largely been neglected in research and policy. A qualitative study was therefore designed to answer the question *'how do adults with severe and profound intellectual disabilities experience intimate care?'* This study was carried out in two residential group homes, and involved the participation of six people with severe and profound intellectual disabilities and seventeen members of staff. Comprehensive methods were used in an original way to ensure that the ethical requirements of gaining consent were met. Data were collected using the ethnographic methods of participant observation, staff interview and document analysis. Following analysis of these data using ethnographic approaches, data analysis tools from grounded theory were used to develop a theoretical explanation for the findings. This research study is the first of its kind and uses a combination of methodological approaches that have not been used to study intimate care in the lives of people with intellectual disabilities before. The outcome of data analysis was that the way that intimate care was delivered varied in the extent to which dignity was maintained or compromised. A multi-dimensional model of dignity has been constructed, and the findings are discussed in relation to the effect of dignity on self-esteem, psychological and physical well-being. This thesis also discusses theoretical explanations for the likelihood of dignity being maintained. It is concluded that, in the main, staff perceived intimate care as physical care and prioritised tasks with visible outcomes, and this may have been at the cost of less tangible outcomes, such as feelings and the subjective experience.



## Chapter 1: Introduction

*'Bathtime. "Dry yourself, I'm not drying those scrawny bollocks of yours. I don't know where they've been. Do it yourself, you lazy bastard"' (Thomas, 1987, p39).*

### 1.0 Introduction

Intimate care is one of the most basic and fundamental human needs. The majority of us take for granted our ability to go to the toilet and wash ourselves in private, and may not have thought much about the impact of intimate care on our quality of life. However, there are people who rely on others to help them with intimate care activities, and these people may have to expose and be touched on, the most private parts of their body on a daily basis. For these people, the way that intimate care is delivered can have the potential to define and drastically alter their quality of life. Despite the importance of this area of care, it is one of the most overlooked themes in academic research.

People with severe and profound intellectual disabilities are amongst those who depend on others to carry out intimate care, and this can be something they experience every day, throughout their entire lives. It is difficult to imagine what it must be like to be on the receiving end of such care, or to identify with the way in which the man was spoken to in the scene above (Thomas, 1987). A study exploring intimate care from the perspective of the people receiving it, can therefore add much to our understanding of this neglected area of research. What is it like for people with severe and profound intellectual disabilities to experience intimate care? This is the question that this thesis attempts to address and therefore make an original contribution to knowledge.

This introductory chapter sets the scene for this thesis by describing the rationale and justification for the study. Additionally, it provides an outline of each subsequent chapter to help guide the reader through the thesis.

## **1.1 Intimate and personal care**

Intimate care is a socially constructed concept and has therefore been defined in a number of different ways, which have largely reflected the operational, political or theoretical purposes for which it has been used. This research is set within the context of service provision for people with intellectual disabilities, and in this context intimate care has been defined as;

*“the care tasks associated with bodily functions, body products and personal hygiene which demand direct or indirect contact with or exposure of the sexual parts of the body”* (Cambridge and Carnaby, 2000a, p6).

Cambridge and Carnaby (2000a) and Carnaby and Cambridge (2006a) have made a distinction between ‘intimate care’ and ‘personal care’, and the activities they assigned to each classification are listed in figure 1.1. According to this classification, the difference between intimate care and personal care is that personal care does not involve exposure of the sexual parts of the body and these activities are more commonly associated with personal presentation, such as brushing hair and shaving.

**Figure 1.1 Activities involved in intimate and personal care**  
(From Carnaby and Cambridge, 2006a)

<b>Intimate care</b>	<b>Personal care</b>
<ul style="list-style-type: none"> <li>• Dressing and undressing (underwear)</li> <li>• Helping someone use the toilet</li> <li>• Changing continence pads soiled with faeces</li> <li>• Changing continence pads soiled with urine</li> <li>• Bathing or showering</li> <li>• Washing intimate parts of body</li> <li>• Menstrual care</li> <li>• Administering enemas</li> <li>• Administering rectal medication</li> </ul>	<ul style="list-style-type: none"> <li>• Shaving</li> <li>• Skin care or applying external medication</li> <li>• Hair care</li> <li>• Help with feeding</li> <li>• Brushing teeth</li> <li>• Applying deodorant</li> <li>• Dressing and undressing (clothing other than underwear)</li> <li>• Washing non-intimate body parts</li> <li>• Prompting to go to the toilet or bathroom</li> </ul>

This thesis set out specifically to study intimate care, rather than personal care. The initial decision to exclude personal care was made because, according to Cambridge and Carnaby's (2000a) definitions, there is something fundamentally different about intimate care and personal care, and therefore it was thought that there may be significant differences in the way that each is experienced. At the outset of the research, it was also thought that examining both intimate and personal care activities would be too broad an area for the scope of this study, and that this would be detrimental to the depth of understanding that could be achieved.

However, once the study had commenced, it was found that intimate and personal care activities were carried out concurrently, and it was therefore difficult to exclude references to personal care during data collection. For example, shaving was considered by Carnaby and Cambridge (2006a) to be a personal care activity, but in the context of this study, was sometimes carried out whilst a service user was having a bath, or sitting on the toilet. Data from interviews also showed that staff did not think of activities as belonging to different categories, as Carnaby and Cambridge (2006a) have suggested, as

they tended to refer to 'personal care' as encompassing both intimate and personal care activities. Therefore, although the focus in this study was on intimate care, and the term 'intimate care' is used throughout this thesis, the findings also include some references to personal care activities.

## **1.2 Background to this study**

The idea for this research originated from my experience of working with people with intellectual disabilities in residential homes, both as a support worker and as a registered intellectual disability nurse. I learnt that there were many people with severe and profound intellectual disabilities who were wholly dependent on others to meet their most intimate care needs, and that intimate care played a large part in their lives. Many of these people were extremely limited in their abilities to communicate their needs and wishes, and to tell the people providing their care how they would like it to be delivered. They were also unable to express their feelings about all aspects of their lives, including being dependent on others for intimate care. Despite the apparent importance and significance of intimate care, I noticed that it was given scant attention in staff training, supervision and organisational policies. My interests and concerns led me to carry out a review of the existing literature of this subject.

This review of the literature confirmed that intimate care is an area that has been relatively neglected in practice and policy. Cambridge and Carnaby (2000a; 2000b; 2002; 2006a) have made the largest contribution to the literature in this area. They found that little attention was paid to this area of care in practice, and that staff in residential and day services for people with intellectual disabilities reported that no specific reference had been made to intimate and personal care in the training they had been provided with (Carnaby and Cambridge, 2006a).

Cambridge and Carnaby's (2002) exploratory research aimed to identify important issues from the perspective of support staff and service managers, and

they have highlighted the importance of intimate and personal care in the lives of people with intellectual disabilities. However, their research did not address intimate care from the perspective of people receiving this care, and neither did it specifically examine intimate care in the lives of people with severe and profound intellectual disabilities. I was particularly interested in gaining an insight into the experiences of people with severe and profound intellectual disabilities because of the level of dependence this group have on others for their intimate care, the amount of time that it takes in their daily lives, and consequently the potential impact that it can have on their overall quality of life.

As I found no published research that has examined the intimate care experiences of people with severe and profound intellectual disabilities an exploratory research study was designed which aimed to answer the broad question;

*How do adults with severe and profound intellectual disabilities experience intimate care?*

A rationale for the use of the terms 'intellectual disabilities' and 'severe and profound intellectual disabilities' is provided in the glossary in appendix 1, where these terms are also defined. In operational terms, the people who this research was about had; an IQ, which if measurable, would have probably been below 35, no verbal communication, and were dependent on others to meet all, or most, of their needs for intimate care.

### **1.3 Methodological approach and overview of this study**

At the heart of this research was a desire to get as close as possible to understanding intimate care experiences from an emic perspective. This posed a methodological challenge for two reasons. Firstly, despite the range of augmentative communication approaches and devices available, people with

severe and profound intellectual disabilities were not able to act as direct informants. It is difficult to study facial expressions, non-word sounds and body language as indications of internal state because they may have a physiological rather than emotional or social origin (Hogg *et al*, 1995). Although it is thought that many people with severe and profound intellectual disabilities are able to communicate intentionally (Bradley, 1998; Grove *et al*, 1999; Dennis, 2003; Ware, 2004), it was beyond the scope of this study to make a valid and reliable assessment of individual behaviour and non-verbal communication as a means of accessing the personal perspectives.

Secondly, research has shown that proxy accounts of subjective well-being lack validity, and Cummins (2002, p197) has therefore argued that *'any attempt to infer another person's subjective state must depend on observable factors'*. Therefore, the sole use of accounts given by care-givers about their perceptions of service user's experiences was excluded from this study.

Consequently was therefore necessary to observe intimate care directly and this posed a second challenge; how to research an area of life that is usually private and beyond the realms of observation. These challenges had implications for the methodological and theoretical approaches that this study demanded. The reasons for deciding to conduct this research within a qualitative, interpretive paradigm using data collection methods of ethnography will be explained in detail in chapter 3.

The use of a methodological approach underpinned by the epistemological philosophy of critical realism has been adopted in this research, and this requires that the researcher reveals their self, makes their personal values explicit and engages in critical self reflection using reflexivity. The importance of reflexivity is discussed in chapter 3, section 3.4, and my personal reflexive account can be found in appendix 2. In keeping with reflexivity, the traditional style of writing research reports in the third person has, at times, been abandoned in this thesis.

This is because the use of the first person ensures transparency and shows that the researcher is an active part of the research process, as well as promoting clear and accurate communication (Webb, 1992).

The ethnographic methods used to collect data required me to spend a number of months observing the delivery of intimate care to service users, interviewing staff and collecting relevant documents in two residential group homes for people with intellectual disabilities<sup>1</sup>. A particular strength of ethnography is in its applicability for studying previously unexplored areas to produce thorough descriptions of a culture, social setting or phenomenon under study (Hammersley and Atkinson, 1995). A thorough description of intimate care was produced as a result of ethnographic data analysis, and this can be found in appendices 19 and 20. However, initial stages of analysis indicated that the data could be interpreted at a deeper theoretical level and a decision was made at this point to continue analysis using data analysis tools from grounded theory.

Grounded theory and ethnography are philosophically and methodologically compatible (Charmaz, 2006), and the decision to combine the approaches was therefore justifiable. A feature and advantage of both ethnography and grounded theory is that it is possible to begin with an open exploratory question and to progressively focus the line of inquiry over the course of the study (Glaser and Strauss, 1967; Charmaz, 2006). In this way the direction of the study can be guided by what is observed (Silverman, 2001). Progressive focussing has been described using the analogy of a funnel; over time the research problem is developed and its scope clarified and delimited, and what the research is ultimately about can be discovered over the course of the study (Hammersley and Atkinson, 1995).

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<sup>1</sup> Definitions of, and rationale for the use of the terms 'service users' 'staff' and 'residential group homes' are provided in the glossary in appendix 1.

In this instance, progressive focussing involved data collection and analysis being carried out in stages, with each stage giving shape and direction for the next. In the first stages of observations concepts were identified which guided me towards what to examine during subsequent periods of observations, and informed the kinds of questions I needed to ask in interviews. Early stages of the investigation indicated that the interaction between care-giver and care-receiver was pertinent for understanding the experience of intimate care, and this suggested that it was appropriate for the data collected to be explored within a theoretical framework of symbolic interactionism.

Symbolic interactionism is a theory that can be used to evaluate social interaction, and this provided a theoretical framework within which further data collection and analysis could be carried out. Progressive focussing in line with symbolic interactionism led to the construction of a more specific research question;

*How does the symbolism that is attached to the way that intimate care is carried out affect the way that it is experienced?*

Therefore, essentially, the perspective of this thesis is that the experience of intimate care can be understood by studying the symbolic nature of the interaction between care-giver and care-receiver. This is based on an underlying assumption that people care about what other people think of them and that they care about the way they are treated. The experience of receiving intimate care was therefore regarded as being inextricably linked to the way in which care is provided.

Data analysis tools of grounded theory were used to discover and analyse the symbolism attached to the way that intimate care was carried out. Analysis involved the identification of themes, and the organisation of these themes into categories. The notion of 'dignity' was a common underlying theme that ran



throughout the data. Dignity recurred with such frequency that it was elevated to the status of a core category, and therefore this became the category around which other themes and categories were organised. It is important to highlight that the emergence of dignity as a core category came as a result of inductive analysis. At the outset of this research, I did not expect my findings to be related to the concept of dignity, as I recorded in my reflexive account (see appendix 2). This suggests that dignity was a valid category because it was discovered directly from the data, rather than being pre-imposed on the data and 'made to fit'.

The data analysed in this study suggested that the way intimate care was carried out, and the way that care-givers communicated with care-receivers varied to the extent to which dignity was maintained or compromised. In order to validate these findings, comparisons were made with the findings reported in papers that had previously been published on dignity and interaction in care settings. The literature reviewed showed that dignity was a complex concept that had been poorly defined. This suggested that to use dignity as a core category in this research, and to develop a shared theoretical understanding of how dignity might be experienced, the concept of dignity needed further clarification. Therefore, data collected in this study was used alongside extant literature to construct a multi-dimensional model of dignity. This model can be found in figure 7.1, chapter 7.

It is important to point out that this literature on dignity was not consulted in the initial review of literature, because to have done so would have been to pre-impose ideas about what might be found, and this would have been incompatible with the qualitative approach used in this research. For this reason, a discussion of the literature reviewed on dignity, and a definition of the concept does not appear until the findings of this research are discussed in chapter 9 (see sections 9.2 and 9.3).

Chapter 9, section 9.4, proceeds to discuss how the extent to which dignity was maintained or compromised might have impacted on experience of intimate care. It is concluded that dignity can have implications for the immediate emotional experience of intimate care and can also have a more long-term enduring effect on psychological and physical well-being. This conclusion has been reached because from a symbolic interactionist perspective, dignity is influential in the development and maintenance of the self-concept and self-esteem. Therefore, the effects of failing to maintain dignity could have devastating consequences for those on the receiving end of intimate care.

In order for this present study to be of value to practice and have the potential to improve quality of care, it was important to consider what might have led to the loss of dignity. Two categories emerged from data analysis which offered explanations for the way that staff interacted with service users, and the way that they carried out intimate care. These categories were named 'attribution of humanness' and 'meaning of intimate care'. The second part of chapter 9 discusses these categories in relation to how well they are able to explain the likelihood that the actions of staff maintained dignity. It is concluded that the staff in this study generally had positive attitudes towards people with severe and profound intellectual disabilities who were in receipt of their care. However, staff's understanding of the purpose of intimate care was to attend to physical aspects of care that had tangible outcomes, and this could lead them to carry out care in a task oriented manner, and to interact in such a way that objectified a care-receiver and compromised their dignity. The implications of these findings are discussed in chapter 10, in the light of the strengths and limitations of this study.

## 1.4 Justification for this research

For ethical and pragmatic reasons, researchers have an obligation to justify that the area of life which they wish to research is worthy of study (RCN, 2004; DoH, 2005). In this thesis, the intimate nature of the area to be studied, and the involvement of people who were unable to give informed consent raised complex ethical issues that made this requirement particularly pertinent. Consequently, the whole of chapter 5 has been devoted to examining the ethical issues raised by this research and the methods that have been used to protect the rights and well-being of all participants.

Clinical governance has provided an impetus for the development of evidence based practice; a process by which decisions are made using best available research evidence, clinical expertise and patient preferences (DoH, 1991; Craig and Smyth, 2002; DoH, 2004; Roe 1998; NMC 2004). In health care, this has been operationalised by the National Institute for Clinical Evidence (NICE), and the government have demonstrated a commitment to research and development in social care practice with the launch of the Social Care Institute for Excellence (CSCI) in 2001.

However, a review of the literature, presented in chapter 2, shows that no research has specifically addressed intimate care in the lives of people with severe and profound intellectual disabilities. There has also been very little research on intellectual disabilities and on intimate care in general. The lack of attention paid by researchers to intimate care may be because it only affects certain groups in society, but is also likely to be because the body and its functions are private matters; often regarded as taboo and therefore not readily researchable (Lawler, 1991). In addition, intimate care is associated with body functions and body products that may evoke disgust and are unappealing to research (Stokes *et al*, 2004).

Furthermore, although 'good theory' is thought to be essential to 'good practice' (Brown and Smith, 1992), chapter 2 will show, there has been almost a complete absence of theory upon which the provision of intimate care in intellectual disability services can be based. Intimate care as a professional activity is also undervalued, and this may have contributed to the minimal attention it has received in policy and training (Wolf, 1986; Twigg, 1997).

Not surprisingly therefore, evidence-based practice in relation to the provision of intimate care has been negligible, and in intellectual disability services, staff have relied on their own values, standards, and experiences to develop methods of care (Cambridge and Carnaby, 2000b). This finding is concerning because practice that is based on personal values can fall short of the standards of safety and quality that have been set in association with 'evidence based practice'. Furthermore, it is known that in services which have poorly developed policies and guidelines there is a higher risk of physical, sexual and psychological abuse (Cambridge and Carnaby, 2000b).

From the perspective of service provision, quality standards and clinical governance, more research focussing on intimate care is therefore long overdue. From an ethical perspective, it is also important that social research focuses its efforts on issues that matter to the people being studied (Minkes *et al*, 1995; Ward and Simons, 1998; Walmsley and Johnson, 2003; Lai *et al*, 2006). Intimate care may not have received much attention from researchers because it has not been thought of as being of particular importance. However, as Bowling (1995, p 1447) has pointed out, the perspective of people who do not have a disability may be irrelevant to the lives of people with disabilities because *'people do not realise what is valuable to them until they have lost it'*.

Determining what is important and matters to people with severe and profound intellectual disabilities is problematic because of barriers to communication. However, Miller (1998) has suggested that if people were asked what they would

miss if they were to acquire a disability, one of the things they are likely to say is the ability to carry out their intimate care for themselves. Furthermore, reports of people who have been dependent on others for intimate care, even for short periods of time, have suggested that the experience can be embarrassing and humiliating for many (Holland *et al*, 2003).

Cummins (2002) has found that proxy raters have tended to underestimate the degree to which normalised life goals are important to people with intellectual disabilities, due to the projection of their own prejudices about the perceived disability. For example, the importance placed on independence, integration and productivity was often underestimated (Cummins, 2002). Therefore the assumption should not be made that what is important to people without disabilities, is not also important to people with disabilities.

Intimate care is something that many people with severe and profound intellectual disabilities have to endure on a regular basis. In residential services bathing is usually carried out at least once a day, and frequent and intensive support may be needed with continence care for the many people with severe and profound intellectual disabilities who experience either urinary or faecal incontinence (von Wendt *et al*, 1990; Smith and Smith, 2003; Stenson and Danaher, 2005). The extent to which intimate care occupies a large amount of daily life indicates that it is likely to have an impact on quality of life (Mirfin-Veitch *et al*, 2004). Therefore, it should be a priority for service providers and care-givers to understand how care-receivers experience it.

Intimate care is also an important area to study because it affects the lives of a large number of people. Whilst data is not available to determine exactly how many people with severe and profound intellectual disabilities depend on paid staff for intimate care, the data that is available is indicative that the issue affects a large number of people, and also that this number is increasing (Clark and Gates, 2006; Mencap, 2001; National Statistics, 2007).

Determining prevalence rates of intellectual disabilities is problematic because of the limited data available, and because of inconsistencies in labelling<sup>2</sup>. No figures have been found pertaining specifically to the number of people with severe and profound intellectual disabilities, but the overall prevalence of moderate and severe intellectual disabilities in the UK has been estimated at approximately 3-4 persons per 1000 of the general population (Open University Press, 1987; Department of Health, 1992; Emerson *et al*, 2001). Clark and Gates (2006) have estimated approximately 230,000 to 350,000 people with severe intellectual disabilities live in the UK.

The definition of 'severe and profound intellectual disabilities' that has been used in this thesis (see appendix 1) includes people who have been labelled as having 'profound and multiple learning disabilities' (PMLD). According to Mencap (2001), PMLD has been the fastest growing group in the population of people with intellectual disabilities, and this escalation has been attributed to developments in medical technology, better control of epilepsy and an increase in the use of percutaneous endoscopic gastrostomy (PEG) feeding. Between 1985 and 2001, the number of children and adults with profound and multiple intellectual disabilities living in England and Wales rose from 25,000 to 40,000 (Mencap, 2001).

This present research applies specifically to people whose intimate care is provided in residential group homes by paid staff, rather than those who have intimate care carried out by unpaid family carers. In 2001, a report published by Mencap stated that sixty percent of people with PMLD lived at home with their parents (Mencap, 2001). This would suggest that forty percent of people with PMLD relied on state services to meet their housing needs, and it is these people who are part of the group this research is relevant to.

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<sup>2</sup> This issue is discussed with the definition of 'intellectual disabilities' in the glossary which can be found in appendix 1.

As well as people with severe and profound intellectual disabilities, the findings presented in this thesis have potential implications for other groups of people who depend on paid staff for intimate care. This might include people with mild and moderate intellectual disabilities, people with physical disabilities, the elderly, people with mental health problems, and people who have an illness or either short-term or long-term health conditions. There is reliable evidence to suggest that the numbers of people in these groups who require intimate care from paid staff is on the rise (National Statistics Online, 2007).

For example, the percentage of elderly people in the UK population is increasing. Between 1980-82 and 2003-05, life expectancy at age 65 had increased by 3.7 years for males and 2.5 years for females, and these figures are predicted to continue to rise (National Statistics Online, 2007). In addition, the number of people with dementia is increasing, and many of these people require support with intimate care (Knapp and Prince, 2007). In 2007, it was estimated there were 700,000 people with dementia in the UK, and this number has been predicted to rise to approximately 940,000 in 2021, and to 1.7 million in 2051 (Alzheimer's Society, 2007).

Furthermore, the number of unpaid carers may be decreasing as more women enter the labour market and have less time for caring in their families and communities (Meagher, 2006). This means that more people will be reliant on paid services to meet their care needs.

To summarise, this research has potential relevance to academic and professional audiences, and the implications of developing an understanding of intimate care could be beneficial to anyone, as we all could become dependent on others for intimate care. This section has shown that this research is justifiable on a number of grounds and has the potential to make valuable contributions to the lives of a large number of people.

## 1.5 Outline of this thesis

This thesis has been written to be clear and transparent and to demonstrate that the requirements of a doctoral thesis by research have been met. However, as Hammersley and Atkinson (1995) have pointed out;

*'The world does not arrange itself into chapters and subheadings for our convenience'* (Hammersley and Atkinson, 1995, p240).

Material has therefore been organised into ten chapters using the conventions traditionally associated with quantitative research, but also commonly adopted in qualitative research reports, because this allows for material to be arranged in a structured and logical order. This involves describing the research chronologically, but a drawback of this is that following the conventions of qualitative methodology, research did not proceed in a linear order. Therefore, it is important to note that the order in which information is presented may give a somewhat inaccurate representation of the order in which the research unfolded.

Before concluding this introductory chapter, a brief summary of the proceeding chapters is provided.

Chapter 2 explores the literature related to services for people with severe and profound intellectual disabilities and intimate care. It identifies where the evidence base is sparse, and explains how carrying out this research within a theoretical framework of symbolic interactionism contributes towards the advancement of knowledge and understanding.

Chapter 3 then discusses the philosophical and political influences on research design and provides a rationale for the choice of methods that have been used to answer the research question.



Chapter 4 progresses this thesis by describing the methods that were used to collect data in two residential homes for people with intellectual disabilities.

In chapter 5 ethical issues are discussed, with particular attention to research with people who lack capacity to consent.

Next, in chapter 6 the process of data analysis and the methods used to increase rigour are described.

In chapters 7 and 8 the findings are presented. Chapter 7 focuses on the core category 'dignity', presents a multi-dimensional model of dignity and describes the categories which related to the way that intimate care was carried out. Following this, chapter 8 describes the categories 'attribution of humanness' and 'meaning of intimate care', which provided possible explanations for the way that intimate care was carried out.

In the penultimate chapter 9, the theoretical implications of the findings are discussed.

Finally, chapter 10 presents the conclusions that have been made from the findings, addresses the strengths and limitations of the study and describes the implications of the findings for policy, practice, and further research.

Throughout the thesis, the reader is referred to a range of appendices for further information and supporting documents. The appendices include a reflexive account (see appendix 2) and a glossary of some of the key and controversial terms that have been used in this thesis (see appendix 1).

## **1.6 Summary and conclusion**

- “ To summarise and conclude, this chapter has laid the foundations for this study by providing background to the research and justifying the importance of the research question that has been asked. The chapter has also described the layout of this thesis, and on these foundations the thesis can proceed with a detailed description of the research. In the next chapter, a review is presented that identifies gaps in the literature, and so presents a theoretical framework within which the research question will be addressed in this study.

## Chapter 2: Review of the literature

*'Theoretically informed and knowledgeable research is not nor should it pretend to be innocent, naïve, or outside the highly political or even politicized areas of knowledge production so characteristic of the 21<sup>st</sup> century' (Clarke, 2005, p75).*

### 2.0 Introduction

The purpose of this review of the literature is four fold; firstly to identify what is known about intimate care in the lives of people with severe and profound intellectual disabilities, secondly to examine the conceptual traditions and research methodologies that have been used to study this area, thirdly to determine where there are gaps in knowledge, and finally to develop a theoretical framework for this study. The chapter also includes an account of how the literature review was carried out.

A broad range of literature from academic, professional and historical texts is included in this review, and it will be noted that it has been difficult to identify papers based on systematic research, which have specifically examined intimate care in the lives of people with severe and profound intellectual disabilities. Therefore, a wider body of knowledge is drawn upon, and it is argued that the subjective experience of receiving intimate care has been neglected in both theoretical and research publications.

Throughout this chapter, an argument is built for the necessity of placing the study of intimate care within a theoretical framework, and the chapter concludes with an explanation as to why symbolic interactionism was chosen as an appropriate theoretical framework for this thesis and how adopting this framework has led to the formulation of specific research aims and questions.

Before moving on to the review of the major works of literature that have contributed to our understanding of intimate care, this chapter commences by discussing the role of the literature review and theoretical frameworks in qualitative research.

## **2.1 The role of a literature review in qualitative research**

The methodological approach for this study is located within the research tradition of ethnography, and the tools used to analyse data derived from grounded theory. The pioneers of grounded theory, Glaser and Strauss (1967) have suggested that conducting a literature review before analysis is complete may cause the researcher to analyse their data through the lens of 'received theory' (Glaser and Strauss, 1967). In a similar vein, Strauss and Corbin (1998) and Vivar (2007) have argued that a purpose of grounded theory is to generate theory inductively from the data, rather than testing an existing theory, and therefore that grounded theory research should not be conducted within an established theoretical framework.

This argument has been challenged (Hammersley and Atkinson, 1995; Clarke, 2005; Charmaz, 2006), and the position taken in this thesis was consistent with Hammersley and Atkinson's (1995) view that as human beings, it is not possible for researchers to be a 'tabula rasa'. Therefore prior knowledge and theoretical ideas cannot, nor should not be removed or separated from the research, but should be embraced and understood through reflexivity. This philosophical position has been called 'critical realism' and will be discussed further in chapter 3, section 3.3.

In this thesis, a view was therefore taken to conduct a full review of the literature prior to the commencement of the study. Furthermore, this decision was supported from an ethical perspective, because it has been argued that a literature review is needed to establish that the proposed study does not ask

questions that have already been answered, and that the area of life to be studied is of significant social importance, and therefore worthy of study (Clarke, 2005; Charmaz, 2006).

The review of the literature therefore influenced the preconceptions that I inevitably took to the area of life that I studied. In keeping with the methodological approach adopted in this study, what was important was that these preconceptions were made explicit through the application of the reflexive process (Hammersley and Atkinson, 1995). For this reason, my reflexive account has been included in this thesis and can be found in appendix 2.

This chapter now moves on to describe how this review of the literature was undertaken.

## **2.2 How the review of the literature was undertaken**

Traditionally, literature reviews in theses review a body of literature that is related to one parent discipline (Perry, 1998). However, the area of life studied in this research; intimate care in the lives of people with severe and profound intellectual disabilities, cannot be accommodated by any one academic or professional discipline. This is because intimate care is a complex phenomenon, different aspects of which have been studied within academic disciplines of biological and medical sciences, and also within the social sciences. Furthermore, there is no body of knowledge that is specific to learning disability nursing (Mitchell, 2004a). It is also apparent from the way that services are configured that both 'intimate care' and 'intellectual disabilities', so to speak, traverse more than one professional discipline.

Historically, since the inception of the National Health Service (NHS), service provision for people with intellectual disabilities in the UK has been located within the NHS (Atherton, 2004). Within many of these services nursing staff have

been involved with the provision of intimate care (Mitchell, 2004a). However, by the end of the twentieth century, the majority of service provision for people with severe and profound intellectual disabilities had been transferred to social care services (Race, 2007), and consequently intimate care was more typically carried out by social care staff. This trend has also been seen in personal and intimate care provision for the elderly (McCormack *et al*; 2000; Scott, 2001).

A review of the literature was therefore conducted across different academic disciplines including those affiliated to biology, medicine and the social sciences and across the professional disciplines of nursing and social care. The professional body I belong to is nursing, and this research was carried out within the Learning Disability Nursing Department of Thames Valley University. Therefore the point of departure for this review of the literature was to consult nursing journals and texts in a systematic review of the literature which was carried out using Ovid in December 2004, and again in February 2008.

The databases that were included in the initial search were; the British Nursing Index 1985-2004, the Cumulative Index to Nursing and Allied Health Literature 1982-2004, EMBASE 1996-2004 and Medline 1966-2004. Some of the major journals (including 'Journal of Intellectual Disabilities', 'Journal of Applied Research in Intellectual Disabilities', 'British Journal of Learning Disabilities' (2001-2004) and 'Journal of Advanced Nursing' (2004)) were also searched by hand for articles which included any of the keyword search terms that are listed in appendix 3.

The review of the literature showed that there had been very little research carried out on, or with, people with severe and profound intellectual disabilities, in any subject area, in comparison to people with less severe intellectual disabilities. Little literature was found to have been published on intimate care, and even less found in relation to the more specific experiences of people with severe and profound intellectual disabilities. The review was therefore extended

to search for literature about intimate care in the lives of the elderly, people with dementia, people with physical disabilities, people receiving care in hospital, people receiving palliative care and people in rehabilitation. It is important to note that there are inherent problems in making generalisations from research about other groups to the lives of people with severe and profound intellectual disabilities, and this will be discussed later in this chapter, in section 2.8.

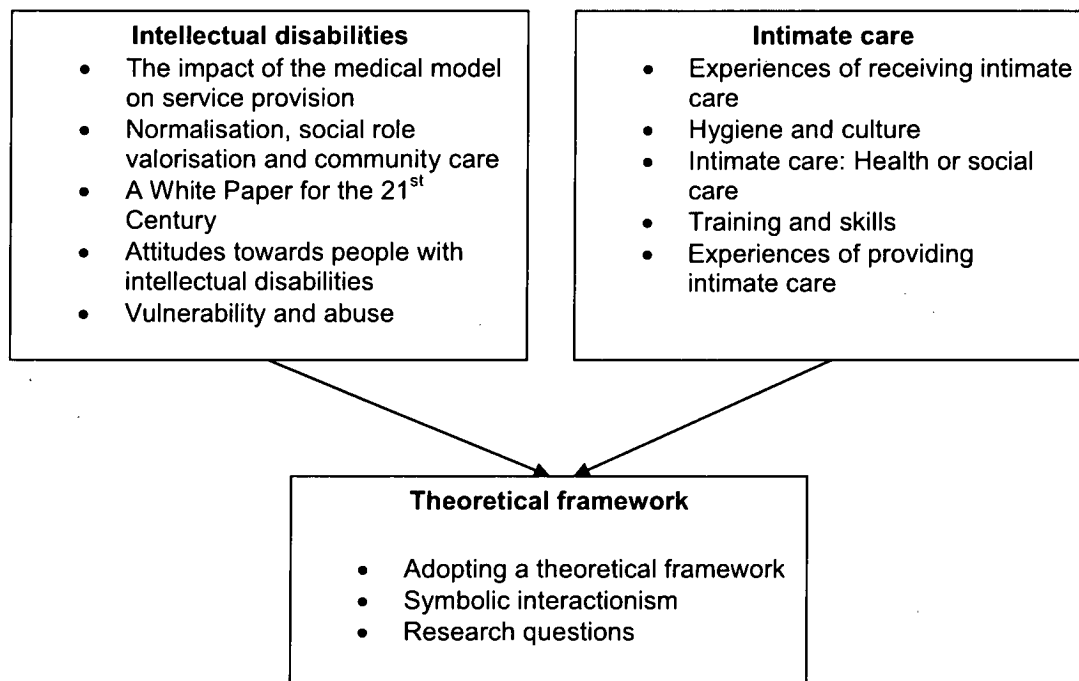
Early stages of the literature review suggested that for people with severe and profound intellectual disabilities the social aspects of intimate care were likely to be important in understanding their experience of care. A review of the literature was therefore also carried out using the International Bibliography of the Social Sciences (IBBS) in August 2006.

In grounded theory, the literature review is not confined to the beginning of the study (Glaser and Strauss, 1967; Charmaz, 2006). The approach taken in this research was to carry out the processes of collecting data, analysing data and reviewing the literature as an iterative cycle, and in this way, the literature could be treated as a source of data (LoBiondo-Wood and Haber, 1998). Preliminary stages of data collection and analysis yielded the tentative identification of a number of themes. Subsequently, these themes were searched for in the literature in order for comparisons to be made. Therefore, the databases were searched a number of times throughout the entire research process, using the keywords that had been identified from data analysis, listed in appendix 3.

The literature reviewed in this chapter has therefore originated from a number of different academic and professional disciplines. One of the challenges of developing and writing this thesis was to organise and synthesise a body of knowledge from such diverse sources. This chapter has been organised to show how the argument that the interaction between care-giver and care-receiver can be studied in order to develop an understanding of how people with severe and profound intellectual disabilities experience intimate care. The organisation of

the rest of this chapter is presented in figure 2.1, and this illustrates how the theoretical framework has emerged following consideration and evaluation of the existing literature related to both the areas of intellectual disabilities and intimate care.

**Figure 2.1: The organisation of chapter 2**



In this review, no research papers have been found that have explored the intimate care experiences of people with severe and profound intellectual disabilities. Our present understanding of how this group of people experience intimate care must therefore be constructed from what we know about the lives of this group in general, and from our understanding of how other groups who are dependent for intimate care have described their experiences. This literature review therefore commences by examining the history and politics behind service provision, how this might affect the provision of intimate care, and therefore the way that it is experienced.



## 2.3 The impact of the medical model on service provision

Throughout the last century our understanding of intellectual disabilities and subsequent models of service provision have been dominated by the medical model, and Ryan and Thomas (1987, p15) have argued that *'medicine has been the main instrument for excluding mentally handicapped people from society'*. In a groundbreaking text, it was argued that the medical model has supported a view that *'subnormality of the individual'*, rather than *'subnormality of the environment'* is to be blamed for the perceived inadequacies of a person to function within a society (Ryan and Thomas, 1987, p27). Psychology has provided similar kinds of theoretical explanations of intellectual disabilities by producing theories emphasising the 'defects' that people with intellectual disabilities are believed to have, and focusing on their differences rather than the similarities they share with the rest of humanity (Ryan and Thomas, 1987; Goode, 1992).

The way in which services have therefore been organised and delivered has been strongly influenced and based on an application of the medical model, and throughout the twentieth century this has seen many people with intellectual disabilities being sent to hospital institutions, where they lived out their entire lives, segregated from the rest of society (Ryan and Thomas, 1987; Sinson, 1993; Parmenter, 2001).

In many respects, Goffman's (1961) influential account of institutional life, gave a damning portrayal of service provision. In this account, Goffman (1961) coined the term 'total institution', which he characterised as having four key features;

- all aspects of life are conducted in the same place
- each phase of the members' daily activity is carried on in the immediate company of others, all of whom are treated alike and required to do the same thing together

- all phases of the day's activities are tightly scheduled to pre-arranged times
- the sequence of activities is imposed from above by a system of explicit formal rulings and body of officials.

Historical texts have documented anecdotal evidence describing what intimate care was like in services, which could have been described as 'total institutions' that has indicated some practices were appalling (Ryan and Thomas, 1987).

For example, Frank Thomas worked at a hospital for the 'mentally subnormal' in the 1970s and over the six month period he was there he kept a diary of his experiences. The following excerpts from his diary illustrated the shocking way that intimate care was carried out.

*'All the lads 'down for a bath' just piled into the bathroom, stripped off, and stood there shivering until their name was called.'*

*'None of the loos have a door on them and a row of lads can be seen squatting on the toilets, in full view of everybody.'*

*'The supply of pants runs out – again. 'Keep your old ones on. Never mind the shit. It didn't bother you before'.*

(Thomas, 1987, p40-41)

Further evidence for the poor conditions within which intimate care has been carried out has been provided by Morris (1969) who found that, in many of the thirty-five hospitals for the mentally handicapped she investigated, the lavatory and bathroom facilities offered no privacy. In a similar vein, communal wash houses in institutions have been described as having '*cramped and squalid washing and lavatory facilities*' (Barton, 1976, p35).

The following excerpt from a report made by Seyman in 1983 after a visit to Normansfield Hospital provides another illustration of the shocking way that intimate care has been carried out.

*'A door was opened to show us one of the bathrooms. A man was in the bath and tried desperately to cover himself from the seven or so strangers. Not once did the nurse address him or apologise for the intrusion. We were appalled and embarrassed and just wanted to get the hell out of there and leave the man to have his bath.'* (Seyman 1983, cited in Merriman, 2007, p9)

During the latter half of the twentieth century, reports and scandals of the inhumane way that people were treated in institutions were brought to the public attention (Sinson, 1993). For example, a report in the Daily Mail on the 5<sup>th</sup> of September in 1977 stated that;

*'Appalling conditions had existed for years. Patients had no privacy in the toilets because broken doors were not replaced. There were no curtains around the baths and showers.'* *'An incontinent patient was scrubbed by a nursing assistant with a toilet brush...'* (Daily Mail cited in Merriman 2007, p199)

And in the 1970's, a BBC Panorama programme showed footage from Leavesden Hospital in Hertfordshire, England of 'patients' with intellectual disabilities, getting out of bed naked and going into a communal washroom where they were washed and dressed together. In this recording, a member of staff reported that he was responsible for getting twenty-four patients ready each morning, with only the help of some more able patients.

An increase in the awareness of conditions like these led to social pressure for better services for people with intellectual disabilities (Race, 2007). The

pressure for change was also fuelled by the emergence of theoretical ideas, named collectively as 'normalisation' and 'social role valorisation'

## **2.4 Normalisation, social role valorisation and community care**

Normalisation is often mistakenly thought of as a single concept, but because different perspectives have been taken on the concept of normalisation, it is more accurate to think of it as 'a family of ideas' (Emerson, 1992). Normalisation emerged from Denmark in 1959 and over subsequent years has undergone reformulation and redefinition. One definition was;

*'Making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and way of life of society'* (Nirje, 1980, p33).

In North America, there was apparent confusion that normalisation meant 'to make people normal'. Consequently, Wolfensberger and Thomas (1983) proposed that normalisation should be renamed 'social role valorisation' as a reflection of the emphasis that they believed should be placed on the importance of devalued people occupying socially valued roles, in order for them to be socially valued (Emerson, 1992; Parmenter, 2001).

Normalisation and social role valorisation was, along with other significant social movements and ideas of the time, behind the emergence of the 'ordinary life movement'. In 1971 Wolfensberger called for the closure of institutions and wrote;

*'On programmatic, ideological, and fiscal grounds, the present institutional system is essentially unsalvageable'* (Wolfensberger, 1971, p36).

In the UK, a policy of community care led to the gradual closure of long stay institutions (Whitehead, 1992; Emerson, 1992). The White Paper *Better Services for the Mentally Handicapped*, was published as a response to the inquiry into allegations of abuse and ill-treatment of vulnerable long stay patients at Ely Hospital in Cardiff (DHSS, 1969). This paper outlined targets for the transference of people with intellectual disabilities to community based settings (DHSS, 1971). The Jay Report, (Jay, 1979) also made recommendations based on a community model of care that were influential in the closure of long stay institutions (Mitchell, 2004b). Over subsequent decades people with intellectual disabilities were gradually moved to residential services, and in the 1980's and 1990's an increasing number of these services were provided by social services, housing associations and voluntary bodies (Nesbitt and Collins, 1998; Mitchell, 2002).

O'Brien's (1980) 'five service accomplishments' attempted to articulate the implications of normalisation in terms of what these new services should try to achieve in the UK. These accomplishments were; ensuring service users are present in the community, ensuring service users are supported to make choices, developing the competence of service users, enhancing respect by developing a positive reputation and ensuring that service users participated in the life of their communities (O'Brien, 1980). A key publication upon which the practical implementation of community care policy was based was the 1988 Wagner report (Sinson, 1993). This report stressed the importance of privacy in residential care, with each person having their own room and personalised space. This clearly had implications for the way that intimate care was provided because intimate care would no longer to be carried out in communal facilities.

Various conceptualisations of the normalisation principle promised to improve the lives of people with intellectual disabilities (Chappell, 1997), and it has generally been accepted that community care has led to better lives for these people (Emerson *et al*, 2000). However, Brown and Smith (1992) have argued that

although institutional services have been relocated in the community, few relevant theoretical models have been available from which to develop good practice and the nature of these services have therefore not been greatly changed or improved. The following quotation expresses a similar opinion;

*'Simply closing institutions does not address the factors that led to their development'* (Parmenter, 2001, p279).

Few contemporary services fit completely within Goffman's (1961) original definition of a total institution. However, residential homes have been regarded as, and labelled as, 'institutions' by virtue of the organisational setting in which care is provided (Penhale, 1999). Sinson (1993) and Roets and Van Hove (2003) have argued that de-institutionalisation must involve more than just moving people, and the term 'micro-institutionalisation' has been coined to refer to;

*'the transference of those institutional practices found in large-scale institutions to their smaller community replacements, allowing the management to assume total control...'* (Sinson, 1993, p78).

## **2.5 A White Paper for the 21<sup>st</sup> Century**

Thirty years after *Better Services for the Mental Handicapped* (DHSS, 1971) was published, a new White Paper, *Valuing People* (DoH, 2001a) was published. This new White Paper acknowledged that although progress had been made towards better service provision, more needed to be done to improve the lives of people with an intellectual disability. This central government initiative paved the way for service development in England to be driven by the principles of rights, independence, respect and choice; the policy being based upon ideology and values, rather than empirically founded theoretical models.

However, it has been argued that the emphasis placed by Valuing People (DoH, 2001a) on independence and choice has failed to acknowledge the kinds of support that people with PMLD need and did not, therefore adequately address the needs of this group (Aylott, 2001, PMLD Network, 2002). Valuing People (DoH, 2001a) has therefore not recognised the heterogeneity of people with intellectual disabilities, and a reluctance to acknowledge the extent to which some people need support can put people at risk from discrimination (Bartlett and Bunning, 1997; McGill, 2005).

People with severe and profound intellectual disabilities have a high level of dependency, and face obstacles in making choices and exercising their rights. They are more likely to experience health problems, and therefore require intervention from the medical profession (Mencap, 2001; Samuel and Pritchard, 2001; Wake, 2004). In comparison to the general population, they are at higher risk of low body weight, pressure sores, constipation, epilepsy, eating and drinking problems (Ganesh *et al*, 1994; Kay *et al*, 1995; Wake, 2004; Arvio and Sillanpää, 2003). They also often have little or no formal language and are dependent on non-verbal methods of communication such as gestures, body language, eye contact and vocalisations and are dependent on others to interpret their non-verbal communication (Samuel and Pritchard, 2001).

Many people with severe and profound intellectual disabilities therefore do need a high level of care. However, Van Loon and Van Hove (2001) have suggested that deinstitutionalisation has led to the concept of 'care' being replaced by the concept of 'support', and evidence of the change in this conceptualisation is that the role of 'care assistant' has been replaced by 'support worker' (Mansell, 1996). This was a sign of the shift in service philosophy towards an ideal of promoting autonomy and independence.

A problem with placing such high value on independence, is that by default it gives negative connotations to dependence, and this can contribute to

diminishing esteem for people who cannot live without support from others (Thompson and Pickering, 2004; Nakken and Vlaskamp, 2002). Intimate care is one area of life that many people with severe and profound intellectual disabilities require full support with, and if services use the principle of independence, in a simplistic way, to underpin care they may have unrealistic goals for these people and fail to provide care that meets their needs. The title of Carnaby's (2006) chapter 'Adults with Profound and Multiple Learning Disabilities – Supporting Planned Dependence' reflects the idea that independence may not be the most appropriate goal for all people with intellectual disabilities.

An emphasis on independence is also reflected in the types of questions that have been asked in the little research that has been carried out on intimate and personal care activities and people with intellectual disabilities. This is because the research has tended to focus on the evaluation of programmes and strategies for increasing levels of independence.

For example, the literature on continence has focused on the implementation and effectiveness of programmes which have aimed to reduce incontinence and increase independence following bowel movements (Stenson and Danaher, 2005; Smith and Smith, 2003; Smith and Smith, 2004; Stokes *et al*, 2004). Menstruation is another example of an aspect of intimate care that has attracted attention from researchers, and again the literature has generally focused on improving independence by teaching women to manage menstruation independently and helping women to understand menstruation (Ditchfield and Burns, 2004; Rodgers 2004; Richman *et al*, 1986; Epps *et al*, 1990; Carlson and Wilson, 1996). A problem with focussing on teaching skills is that if practices of training to increase independence become the dominant modes of engaging with people with intellectual disabilities, it can be at the cost of the service users' subjective experience of their care (Klotz, 2001).



Two noteworthy exceptions to the research that has focused on teaching skills and independence were studies by Carlson and Wilson (1996) and Rodgers (2000). Carlson and Wilson (1996) have highlighted the lack of attention paid by previous research to the needs of women who were not able to become independent in managing their menstruation. They have concluded from their own research, that staff lacked training in how to provide menstrual care and how to make decisions about its management for women who needed support and therefore found this aspect of their work difficult. In Rodgers' (2000) study the majority of women with intellectual disabilities interviewed reported negative views about menstruation and feelings of lack of control. These studies have added weight to the argument that there is a need for a greater understanding of the intimate care needs of people for whom independence may be an unrealistic service objective.

Therefore, arguably the focus that policy, research and practice have placed on independence has led to disregard for the needs of people with severe and profound intellectual disabilities. Dependence is undervalued by society, and in Western society a person's worth and status is determined, in part, by their ability to look after themselves and manage their own affairs (Keith, 1992). The need for intimate care given by another is, according to Edgerton (1967), the 'most stark' example of a person's incompetence. It therefore follows that less value is placed on dependence on others for activities such as intimate care, and this is reflected in the efforts of policy, research and practice on increasing independence. It has been suggested that intimate care does not sit comfortably within the ordinary living philosophy because, through the medical model, we have been conditioned to think of curing disability rather than finding ways of accepting difference (Carnaby and Cambridge, 2006a).

A result of this failure to accept difference can be seen in a common assumption that, despite the fact that none of us live entirely independently, people who are largely dependent on others will have a poorer quality of life (Keith, 1992; Hogg,

1998). This assumption has led some people to question the value of the life and the right to life of people with severe and profound intellectual disabilities. The following section of this chapter discusses the literature that pertains to this issue, because attitudes towards people with severe and profound intellectual disabilities are relevant for understanding how care is provided to them.

## **2.6 Attitudes towards people with intellectual disabilities**

Mencap (2001) have argued that despite the degree of impairment faced by people with profound and multiple learning disabilities, some of the greatest problems this group are at risk of are created by other people's damaging attitudes. History has seen people with intellectual disabilities being placed on the outside, or at best the fringes of society because;

*'their humanity has been denied, they have been seen as a threat and a danger to society, they have been oppressed and segregated'* (Parmenter, 2001, p275).

Braddock and Parish (2001) have also argued that during the latter half of the twentieth century, the normalisation principle had a significant impact on changing society's perception of the basic humanity of people with intellectual disabilities. However, their right to life has continued to be debated (Wolfensberger, 1994; Hogg, 1998), and writing in the late 1980's it was asserted that;

*'People with learning difficulties are the most oppressed of all minorities. They are rejected and sentimentalised over as objects of pity, mawkishness and whimsy'* (Brandon, 1989 p96).

Clark and Gates (2006) have argued that there remains considerable ignorance both in the general public, and health and social care professions about people

with profound intellectual disabilities and complex needs. The following statements made to parents of people with profound intellectual disabilities and complex needs reveal some disturbing attitudes of the public and professionals alike;

*'I went to Tesco's and a woman said 'fancy bringing someone like that in here' (Mencap, 2001, p17).*

*'The doctor said: 'You have a beautiful daughter with the brain of a cabbage.' (Mencap, 2001, p22).*

*'Victoria was rushed to hospital after a series of seizures: She needed to be put on a ventilator. The Doctor came up and spoke to us. He was suggesting that it wasn't worth trying to save her' (Mencap, 2004, p19).*

Mencap followed up their 2004 *'Treat Me Right'* report with *'Death by Indifference'* (Mencap, 2007), which highlighted how shocking inadequacies in the National Health Service had led to tragic and fatal consequences for people with intellectual disabilities and their families. The report suggested that institutional discrimination was at the root of this, and that a contributing factor towards institutional discrimination was the attitudes of professionals about the quality of life, and therefore right to life, of people with intellectual disabilities. However, the PMLD Network (Mencap, 2001) have argued vehemently that people with profound intellectual disabilities and complex needs have a fundamental right to life and the Human Rights Act 1998 has enshrined the right to life in law for all human beings. Both Lacey (1998) and the PMLD Network (2007) have also pointed out the positive contributions that people with intellectual disabilities make to the lives of people around them and that they can, and do live socially meaningful lives.

However, negative and dehumanising attitudes towards this group have continued to prevail and this is one reason why the group have been vulnerable to abuse. This issue of dehumanisation is returned to in section 9.9 of chapter 9 when the findings of the study are discussed. The next section discusses the vulnerability of people with severe and profound intellectual disabilities, how this puts them at risk of abuse in the context of intimate care and the implications this has for the present study.

## **2.7 Vulnerability and abuse**

Brown and Craft (1989) have highlighted the widespread physical, sexual, emotional and financial abuse and neglect that has been evident in some services for people with intellectual disabilities. People with severe and profound intellectual disabilities have been one of the groups most vulnerable to abuse in western society. This has been a consequence of the high level of dependence they have on others for their survival, the degree of communication difficulties they experience, and as previously discussed, the prevalence of attitudes towards this group that have denied their humanity and basic right to life (Walmsley, 1989).

'No Secrets' was published in 2000 with the aim of ensuring that local agencies were able to work together to protect vulnerable adults from abuse through the development of multi-agency policies and procedures (DoH, 2000a). However, six years after the publication of 'No Secrets', it was clear from reports of abuse in services, such as some of those provided by the Cornwall Partnership NHS Trust, that more needed to be done (Commission for Healthcare Audit and Inspection, 2006).

Research has shown that abusers are most often people who are known to the victim, and someone in a position of care or power (Brown, 1995; Joyce, 2003; White *et al*, 2003; McCormack *et al*, 2005). This means that people with

intellectual disabilities can be at most risk in their own homes. Intimate care is usually carried out in private, and this puts service users at particular risk, because abuse in intellectual disability services has been found usually to happen when the perpetrator and victim are alone (Cambridge and Carnaby, 2000a; Joyce, 2003). Intimate care involves exposure of the sexual parts of the body and is therefore an opportune time for abuse to occur (Cambridge and Carnaby, 2000a). Furthermore, this discussion is pertinent to the present study because these risks are greatest for people with more severe intellectual disabilities (Cambridge and Carnaby, 2000a).

Because intimate care is not open to scrutiny, it is not possible to ascertain the exact extent and scale of abuse that occurs within this area of practice. Cambridge and Carnaby (2000a) have addressed important issues around the risk of abuse in intimate care and made recommendations as to how these risks could be reduced through policy and practice. Their recommendations focused on; the risks involved in the employment of agency staff, staff competencies and training, meeting culturally diverse needs, standards of care management and record keeping and management and supervision.

In relation to intimate care, defining what constitutes abuse is not straight forward. For example, in most situations taking off someone's underwear and touching the sexual parts of the body without their explicit consent would be considered abusive, yet this is what can happen every day to someone with a severe intellectual disability when supported with intimate care (Cambridge and Carnaby, 2000a). It may also be problematic to determine if certain interactions should be considered to be mildly unkind or insensitive or, more seriously abusive. Anecdotal evidence has suggested that service users are often subjected to abuse that is not acknowledged or dealt with by the services in which it occurs.

For example, Aylott (1995) has recalled an incident from her days as a student nurse which illustrates an incident which could be considered to be abusive;

*'On two separate occasions as a student I heard staff laughing and mocking a young man with a learning disability as he undressed for the bath' (Aylott, 1995, p1111).*

In Mirfin-Veitch *et al's* (2004) study, which will be discussed in more detail later in this chapter, one woman with mild intellectual disabilities said that support workers had been unpleasant to her because they had thought that she should have been able to control her bowel movements. This led to her feeling nervous about having an accident and losing control of her bowel movements in the future and fearful of the support worker who had been unpleasant to her.

Another problematic area is how to determine when culturally inappropriate practice becomes abuse. The literature on intimate care largely fails to shed light on the cultural variations in the provision of intimate care, and intellectual disability services have been blamed for failing to recognise the intimate care needs of people from ethnic minorities by organising services to conform to the 'white norm' (Shah, 2006).

The discussion thus far illustrates the difficulty of determining exactly what constitutes abuse in relation to intimate care. Without clear standards and guidance to remove ambiguity, the risk of abuse can be greater for people who rely on services to meet their care needs (Cambridge and Carnaby, 2000a). In order for this problem to be resolved, a deeper understanding is needed about how intimate care is provided and further how it is experienced, and this understanding is lacking from the current body of knowledge.

This then concludes the review of the more general literature on the lives of people with intellectual disabilities and more specifically the lives of people with

severe and profound intellectual disabilities. Although this literature has not addressed intimate care specifically, what can be deduced is that historically and to date, intimate care has not always been carried out in privacy, and a lack of guidance and protective procedures and policies has placed people with intellectual disabilities at risk from abusive practice. A lack of privacy in the delivery of intimate care can be seen as abusive, but maintaining privacy may also allow abuse to occur because it can go on unseen. This chapter now moves on to review the literature on intimate care and commences by discussing the literature that relates specifically to experiences of receiving intimate care.

## **2.8 Experiences of receiving intimate care**

As stated earlier in this chapter, no research has been found specifically to address intimate care in the lives of people with severe and profound intellectual disabilities. This section therefore reviews literature on intimate care and people with mild or moderate intellectual disabilities, people with physical disabilities, the elderly and those who have required intimate care whilst in hospital. It is important to note that there are limitations with drawing inferences from the experiences of other groups to people with severe and profound intellectual disabilities. Toombs (1995) has pointed out the difference between the experience of someone who has had abilities and then lost them, and someone who has never had those abilities. People with profound and multiple intellectual disabilities have a need for highly intensive, life long support in almost every aspect of their lives (Mencap, 2001). This means that the way they experience intimate care might be different to people who have been dependent for shorter periods of time, such as when ill in hospital, or during older age.

Whilst recognising that individuals with severe and profound intellectual disabilities have specific needs and unique experiences, which may be different to other people, it must also be remembered that we all share a common humanity (Ryan and Thomas, 1987). One assumption about people with

disabilities is that they do not have the same need for privacy as the non-disabled, because they become accustomed to having their privacy invaded (Evans, 1991; Mirfin-Veitch *et al*, 2004). However, this assumption has been discredited by people with disabilities including Toombs (1995), who has described the shame that she experienced as a result of being dependent on others, and Mirfin-Veitch *et al* (2004) who have found that people with intellectual disabilities can feel embarrassed because of needing help with intimate and personal care.

Therefore, although the psychological effects of depending on others for intimate care have not been systematically researched, it is thought that being dependent on others for intimate care is humiliating for most people and robs them of their dignity (Rogers, 1990; Holland *et al*, 2003). This view was supported by Burton (1993), who has suggested that the first experiences of receiving intimate care are at best embarrassing and at worst terrifying. Miller (1998) has also suggested that when people were asked what they would miss if they were suddenly to acquire a disability, the responses that were given included the ability to self care, to wash and to use the toilet independently.

Mirfin-Veitch *et al* (2004) have presented a paper at the International Association for the Scientific Study of Intellectual Disabilities (IASSID) World Congress on their research which aimed to explore, describe and interpret the experience of receiving and providing intimate and personal care. The paper reported findings from interviews with four people with intellectual disabilities who were living in New Zealand in community group homes for adults with 'high support needs'. This research provided some noteworthy anecdotal insights, and suggested that for these individuals, the way that intimate and personal care was carried out impacted on their quality of life (Mirfin-Veitch *et al*, 2004).

A prominent theme of Mirfin-Veitch *et al*'s (2004) study was for participants to talk about the quality of the interaction they experienced with the person providing



their intimate care. Participants said that they valued being treated in a friendly, caring manner and with respect. One participant said that what made a good carer was someone who enjoyed their work and liked to be with the person they were caring for. People who did not make good carers were described as *'people who say you are useless, that you can't do anything'* (Mirfin-Veitch *et al*, 2004). Participants also described times when they had felt rushed during intimate care and according to Mirfin-Veitch *et al* (2004), they would have liked to have more time to *'interact at a deeper level'*.

The three women who were interviewed all talked about the differences between being cared for by their own mothers, in comparison to the care provided by support workers in community based settings. These women said that they had preferred being cared for by their mothers and one participant explained that the difference was that her mum loved her. Another participant thought that the reason she had a more positive experience of being cared for by her mother was because her mother had a greater understanding of her. Mirfin-Veitch *et al* (2004) have concluded that it was an absence of emotion in the care interaction provided by support staff that contributed to these women's poorer experiences of intimate and personal care. In a similar vein, Meagher (2006) has been pointed out that;

*'paid carers meet our needs not because they love us but because it is their job to do so'* (Meagher, 2006, p34).

The only male participant in Mirfin-Veitch *et al*'s (2004) study talked about how his experiences of intimate care had improved since moving from an institution to a community setting because community care had offered him greater choice and control. However, it is not clear whether this experience would be shared by people with more severe intellectual disabilities because, as Cambridge and Carnaby (2000a) have suggested, people with more severe intellectual

disabilities are less likely to be able to exercise power and control in their lives than those who are able to self-advocate.

Another source of evidence of the psychological effects of depending on others for intimate care comes from the literature on adults with dementia. This literature reveals that for people with dementia, bathing can be experienced as unpleasant and frightening (Rader, 1996; Dunn *et al*, 2002; Sloane 2004; Cohen-Mansfield and Biddison, 2005). Rader (1996) and Dunn *et al* (2002) have suggested that the traditional way bathing is carried out can be particularly frightening and that alternatives, such as towel baths and bed baths, should therefore be considered. This research suggests that staff should be mindful of the fear that can be experienced and to do what they can to minimise that fear. Arguably, bathing may also be particularly frightening for some people with intellectual disabilities, but the literature indicates that alternatives have rarely been considered in this field.

The literature reviewed has suggested that experiences of intimate care are likely to be greatly affected by the way that the person providing care interacts with them. Therefore, understanding the experience of receiving intimate care cannot be separated from understanding the provision of that care, and this meant for the purposes of this study it was important to examine the wider literature on intimate care and the cultural, political and professional influences on the way in which it is carried out. This chapter progresses to discuss the wider literature on intimate care and commences with a discussion of hygiene and culture.

## **2.9 Hygiene and culture**

The value that contemporary western society places on cleanliness derives from the belief that hygiene is important for the prevention of disease and illness (Wolf, 1986). However, it was not until around 1530 that defecating in public became unacceptable (Elias, 1978), and the mid nineteenth century that bathing

became common place for the majority of western society (Twigg, 1997). According to Greene (2001) the spread of human disease reduced following such improvements in personal hygiene. However, the precise nature of the relationship between hygiene and health has not been well established (Twigg, 1997).

The way in which hygiene issues are dealt with probably derives more from social and cultural norms than from 'scientific evidence' of clinical and biological requirements for maintaining hygiene (Spiller, 1992; Skewes, 1997). Twigg (1997, p211) has provided an account of bathing throughout history which has shown that it is not '*a straightforward, universal or common-sense procedure*', but that the meaning and practice of bathing has shifted over time.

Anthropologists, who have studied intimate care rituals, have shown that societies and cultures have different beliefs about cleanliness and different practices for maintaining hygiene, which are not always based on biological evidence (Lawler, 1991; Twigg, 1997; Clark, 2006b). Some of these cultural differences have been discussed by Holland and Hogg (2001), Holland *et al* (2003) and Clark (2006b).

In western society there is stigma attached to bodily uncleanliness and odour (Spiller, 1992). However, in some societies and cultures body odour is considered to be socially acceptable and 'normal', and ideas about how often bathing should take place vary considerably (McMahon and Harding, 1993; Skewes, 1997). Clearly there is no definitive 'right' or 'wrong' with regard to standards of cleanliness and body odour, and this potentially poses a dilemma for carers supporting people who come from a different cultural background to their own, or are resistive to bathing and washing.

The concept of intimate has therefore been constructed, not only on discourses related to hygiene, but also around social discourses. For example, bathing has been regarded as a source of health, luxury and pleasure, relaxation and

invigoration (Twigg, 1997; Wolf, 1986). This may have prompted the political debate over whether intimate care should be a health or social problem, which is a debate that has also been driven by the cost implications of determining whose responsibility it is to provide intimate care (Young, 1991). Much of the literature on intimate care has consequently been dominated by these discussions. This next section examines the 'health or social care debate' and considers its relevance to intimate care in intellectual disability services.

## 2.10 Intimate care: health or social care?

The maintenance of personal cleanliness has been fundamental to nursing since the time of Florence Nightingale (Whiting, 1999), and in both The Royal Commission's (1999) recommendations on Long Term Care, and the Essence of Care (DoH, 2001c), intimate care fell within a definition of nursing. The Essence of Care (DoH, 2001c) included personal and oral hygiene, continence, bladder and bowel care in its eight fundamental aspects of care and saw nurses as being central to the provision of that care. The Royal Commission (1999) has defined personal care as;

*'the care needs, often intimate, which give rise to the major additional costs of frailty or disability associated with old age' and 'care that directly involves touching a person's body, and is distinct from treatment / therapy'* (The Royal Commission, 1999).

The NHS and Community Care Act 1990 has stated that it was the duty of local authorities to assess for social care and support, and the 2000 NHS Plan, pledged to fund nursing care through the NHS, with social care to be paid for through local authority social services. The Government of the time therefore tried to tease out social care activities in order to shift the responsibility for their funding from the NHS to local authorities (Young, 1991). According to MacAlister (2001) the Government subsequently decided that intimate and personal care

should be carried out under the responsibility of social care services (Young, 1991; MacAlister, 2001). Although nurses continued to provide intimate and personal care in some settings, such as in hospitals and nursing homes, in many cases the delivery of such care was transferred to social care services.

The decision to remove intimate and personal care from the responsibility of nurses was met with opposition by the nursing profession. A number of commentators argued that intimate and personal care were fundamental to nursing care and that as skilled health activities they should be carried out by trained health professionals (McCormack *et al*, 2000; Rader, 1994; Cambridge and Carnaby, 2000a; Scott, 2001; MacAlister, 2001).

This debate, although not directly related to people with intellectual disabilities, is important to include in this thesis because it highlights a view that intimate and personal care are skilled activities. As discussed earlier in this chapter, in intellectual disability services there has also been a shift from 'care' being carried out by qualified nurses within institutions, to 'support' being provided by unqualified staff in community based residential services (Mansell *et al*, 2002). The implications of the lack of qualified staff in intellectual disability services are discussed in this next section.

## **2.11 Training and skills**

Whereas nursing is a recognised skilled profession, social care work has not been acknowledged as both skilful and demanding, and therefore training, support and supervision have been scarce in this field (Laming, 1999). Few social care staff have been members of professions (Meagher, 2006) and few have had relevant care-related qualifications (Mansell, 1996; DoH, 2001a; Clark and Gates, 2006). In 1999 it was estimated that approximately seventy-five percent of the intellectual disabilities workforce was unqualified (Ward, 1999).

The lack of trained and experienced staff is also thought to result from high stress and low staff morale that has been reported as being widespread in these services (Hatton *et al*, 1999). This is important because staff stress and morale have been identified as issues affecting the general quality of services for people with intellectual disabilities (Hatton *et al*, 1999).

The White Paper, Valuing People (DoH, 2001a), recognised that the lack of trained staff needed to be addressed and introduced the Learning Disability Awards Framework (LDAF). A target was set that by 2002 all new entrants to learning disability services should be registered for an LDAF qualification and by 2005, fifty percent of front line staff should have achieved at least NVQ level 2 (DoH, 2001a). However, Forbat (2006) has suggested that LDAF has fallen short of needs and expectations. Consequently, staff may not have had any training that has addressed the theoretical aspects of their work, and although they may have been shown what to do during induction and in house training, they are unlikely to get any explanation about why things are done in a particular way (Carnaby and Cambridge, 2006b).

Carnaby and Cambridge (2006b) have found that in the absence of detailed training, supervision and guidance on intimate care, staff have relied on shadowing more experienced staff to determine what they should do. Staff have also taken an empathic approach to intimate care and use their own preferences and experiences of caring for family members to determine how to go about providing informal intimate and personal care (Cambridge and Carnaby, 2000a). This approach to providing intimate care has been supported by the Domiciliary Care Standards (DoH, 2003a) which have made it clear that service provision should be based on the principles of dignity, respect and privacy and responsibility for ensuring that these principles are met was placed with care and support workers who should '*treat others as they would wish to be treated themselves*'. Arguably, this statement is tautological, adding nothing of value, because in these standards the Government stated that the test of whether these

principles are put into practice or not is a matter for personal judgment. Carnaby and Cambridge (2006a) have concluded that a failure to establish competencies and relying on personal constructions can lead to inconsistent, value-laden and institutional practices. As this chapter has shown, this can lead to practices that could be experienced as inhumane and abusive.

Furthermore, according to Cambridge and Carnaby (2000a), the policies and procedures that have been available have been based on ideas of 'best practice' and have been found by staff to be too vague to be of much use. Cambridge (2006) has highlighted the problem of deciding who should determine what constitutes best practice. These authors have therefore concluded that, in residential settings, there has been *'little if anything observed in terms of quality standard setting or discussion of good practice'* (Cambridge and Carnaby, 2002).

In response to this problem, and the lack of training available, Cambridge and Carnaby (2000b) produced a staff training resource entitled *'Intimate and personal care for people with intellectual disabilities'*. This, comprehensive training pack, covered a broad range of topics related to this area of practice and included case studies and pictures to prompt discussion of what might constitute good and bad practice, as well as suggestions for improving quality of care. However, the effectiveness of the training relies on the skills and knowledge of a trainer or facilitator, and because the pack prompts discussion without always giving constructive and specific guidance about how intimate and personal care should be carried out, it is probably fair to say that more questions are asked than answered. In terms of evaluating this resource, the literature review that was carried out for the purposes of this thesis did not reveal any published research on its uptake, use or effectiveness. The resource was underpinned by research which examined staff perspectives (Cambridge and Carnaby, 2000b). Arguably the validity of such a resource could be improved by developing a greater understanding of the service user's perspective.

It is conceivable that the lack of training that has been provided on intimate care is, in part, a consequence of the low status that is ascribed to social care and intimate care, both within services and by the wider society (Lawler, 1991).

Intimate care has been regarded as 'dirty work' and as 'women's work', both of which have been devalued and underpaid (Wolf, 1986; Benner and Wrubel, 1989; Lawler, 1991; Downs, 1998). Further, this lack of training and preparation for intimate care has been blamed for some of the negative experiences that have been reported by nurses who have been required to carry out intimate care (Lawler, 1991). This chapter now moves on to examine what is known about the experience of providing intimate care from the care-giver's perspective, and considers the impact that this might have on the care-receiver.

## **2.12 Experiences of providing intimate care**

In western cultures, it is more acceptable to touch certain parts of the body than others and in the UK, Lawler (1991) has described how there is a 'non-touching' culture which must be overcome by carers who need to touch other people's bodies as part of their professional role. These attitudes towards touch and also to body exposure have implications for the management of intimate care (Lawler, 1991).

Nurses and student nurses have reported that their first experiences of providing intimate care have been stressful and frightening (Seed, 1995; Higginson, 2006; Clark, 2006a). Common worries for pre-registration nurses prior to being placed in practice settings included dealing with bodily fluids, and washing intimate parts of patient's bodies (Higginson, 2006). Lawler (1991) and Seed (1995) have found that when nurses first had to undress patients and confront their naked bodies, they had feelings of terror, embarrassment and timidity and this was most profound when female nurses had to deal with male bodies and particularly when the genitalia were exposed.



However, the nursing profession has a strong identity which allows nurses access to the body. Lawler (1991) has suggested that the nurses uniform offers protection in dealing with crossing the boundaries of normal interaction, and this was supported by neophyte nurses who reported that *'wearing a uniform legitimized them in crossing boundaries'* (Seed, 1995, p1136). Staff working in social care settings who do not belong to a profession and do not wear a uniform may therefore find these issues more difficult to deal with.

Research has shown that there are some aspects of intimate and personal care that staff prefer over others. Generally, staff have said that they prefer personal care tasks to intimate care tasks, and for some staff intimate care is the least liked part of their work (Wolf, 1986; Cambridge and Carnaby, 2002). One explanation for staff preferring personal care tasks over intimate care tasks is that humans have an innate tendency to shrink from objects which are considered 'slimy to touch' (Knapp, 1967). According to Lawler (1991), certain body products induce negative emotional responses, and Kubie (1937) has constructed a 'hierarchy of dirt' based on Freudian ideas which suggests that certain body products are considered to be more dirty than others. This hierarchy is embedded in the unconscious with tears being considered the cleanest and urine and faeces among the dirtiest. Lawler (1991) has concluded that there is a close association between the body, sexuality and dirt, and the social mechanisms that proscribe how they are dealt with, and that;

*'In our society there is the notion of the 'civilising process' which locates our particular ways of dealing with the body, sexuality and dirt within a privatising context...'* (Lawler, 1991, p82)

It is perhaps, therefore not surprising that some of the least liked activities by staff working in a variety of care settings involve bowel and bladder functions (Atkins *et al*, 1982; Lawler, 1991; Cambridge and Carnaby, 2002).

Staff's apparent dislike for certain intimate care activities might impact on their ability to provide care in the most sensitive way. For example, staff have been found to use speed, routine and ritualised practice to deal with the embarrassment of providing intimate care (Seed, 1995). This is one of the areas that has received the most attention in the nursing literature on intimate care.

Ritual action, according to Walsh and Ford (1989a, p26) *'implies carrying out a task without thinking it through in a problem-solving logical way'*, and this means that things might get done in a certain way because that is the way they have always been done. As an example of ritualistic practice, Walsh and Ford (1989b) have suggested that the daily bath has been 'drummed into' student nurses and the practice of morning bathing has subsequently been carried out on wards without thinking about the needs of individual patients.

Daily bathing is therefore based more on 'cultural norms', or 'institutional norms' than clinical requirements, and despite the risks that are associated with bathing, which include cross infection and dry skin conditions (Walsh and Ford, 1989b; Skewes, 1997), nurses generally think;

*'that a daily bath does their patients good and rarely does harm. Nurses consider the bed bath an opportunity to inspect patients' skin, to insure the health of the skin, and to provide comfort, respect and dignity for their patients'* (Wolf, 1986, p32).

Bathing provides nurses the opportunity to impose order, and nurses have reported that they have felt they were not doing a good job if they did not bathe patients every day (Wolf, 1986; Spiller, 1992). Menzies (1970) has argued that the consequences of ritual action can be to dehumanise the patient by subjecting them to a set of routines.

In the context of intellectual disability services, Cambridge and Carnaby (2002) have also found that social care staff tended to carry out intimate and personal care in a routine and task oriented way, and have argued that this can prevent intimate care being used as an opportunity for quality communication and interaction.

As previously stated, Mirfin-Veitch *et al* (2004) have concluded that the experience of people with intellectual disabilities receiving intimate and personal care is an emotional one. In relation to hospital care, Attree (2001) has also found that patients placed greater emphasis on inter-personal interaction than on the technical aspects of care, and this finding has been replicated in a study on quality of care in a psychiatric setting (Shcröder *et al*, 2006). In contrast, what appears to be important to staff is the visible tasks and 'getting the job done' to maintain order and appear to be hard working and productive (Wolf, 1986; Spiller, 1992; Lau *et al*, 2007).

The focus on physical care and its apparent priority over invisible aspects of care is reflected in many of the major nursing texts which contain procedural and technical advice on what to do to maintain patients' hygiene and prevent cross infection (Greaves, 1985; Gooch, 1989; Rogers 1990; Gray *et al*, 2002; Cooper, 1993; Wolff Lewis and Kuhn Timby, 1993; Ashurst, 2003; Holland *et al*, 2003; Parker, 2004; Wheeler and James, 2006). Literature from other sources, such as carer manuals, has also tended to focus on practical issues about what to do, rather than how to do it (for example; McMahon and Harding, 1993, Wolff Lewis and Kuhn Timby 1993, and Holland *et al*, 2003).

This suggests a discrepancy between what is important to care-receivers and care-givers in the way that intimate care is carried out, and these priorities can be understood as relating to different levels of Maslow's hierarchy of needs (Maslow, 1970). Carnaby and Cambridge (2006a) have argued that intimate and personal care permeates most levels of Maslow's hierarchy of needs. However,

the priorities that staff have for cleanliness and efficiency (Wolf, 1986; Walsh and Ford, 1989; Seed, 1995) relate to basic physiological needs, which are located at the bottom of the hierarchy, and the importance care-receivers apparently place on interaction relate to self-actualisation, self-esteem, belongingness and love, which are located at a higher level of the hierarchy. Therefore, care-givers whose only concern is for meeting basic physiological needs might fail to interact with care-receivers in a way that meets needs that relate to higher levels of the hierarchy.

The review of the literature has shown that what is important to many people on the receiving end of care is their feelings and emotional reaction to the way that care is carried out. The aspect of experience that this thesis is concerned with is therefore the care-receiver's feelings and their subjective reaction to intimate care, and this is largely determined by the interaction that takes place with their care-giver. The importance care-receivers place on interaction during intimate care suggests that in order to develop a theoretical understanding of the experience of intimate care, it is necessary to pay attention to, and explain the interaction that takes place. Keith (1992) has suggested that;

*'It is both unhelpful and unproductive to polarise the needs of disabled people and their carers and treat them as if they are mutually exclusive'* (Keith, 1992, p167).

However, the research that has been carried out on intimate care has not attempted to unify the experience of giving and receiving intimate care, and the literature has also failed to offer any theoretical insights into how people might experience intimate care. This has arguably been a result of the difficulty of locating intimate care within any one academic discipline, and the lack of systematic research studies that have been carried out on the subject. Therefore, the problem of locating intimate care in the organisation of knowledge parallels the problem of locating the study of the body within an academic

discipline, which Lawler (1991) has referred to as the 'problem of the body'.

According to Lawler (1991);

*'although a social and human body is integral to our existence, no discipline has yet overtly, explicitly and theoretically accommodated it, except in pieces.'* *'Our understanding of the body has been constructed in terms of the separate mind and body and not one entity of mind and body'* (Lawler, 1991, p2).

The location of nursing as a profession allied to medicine has meant that a dualist approach has been taken whereby mind and body have been viewed as separate entities. This has led to studies within nursing being underpinned by the medical model. According to Parker (1997);

*'Historically, the study of the body in nursing has been undertaken almost exclusively within the scientific discourse of modern medicine'* (Parker, 1997, p11).

Allegiance to the medical model has led to emphasis on the body as a physical object, and this has been at the cost of attending to human experience, embodiment and intersubjective interaction (Peters, 1995; Parker, 1997). The application of the medical model in nursing is therefore problematic because;

*'A particular focus of nursing is the whole person and the human response rather than a particular aspect of the person or a particular pathological condition'* (RCN, 2003, p3).

This problem could also be applied to social care because, as Lawler (1991) has argued, the disorganisation of knowledge about the body in the social sciences literature has illustrated the difficulties that sociologists have had with placing the body within social theory. The literature on intimate care reviewed in this chapter

that has attempted to traverse both biological and social boundaries has generally been found in professional literature. Subsequently it has not reflected formalised bodies of knowledge and has lacked theoretical cohesion. Lawler's (1991, p3) argument that the body has been located '*beyond the margins of legitimate and mainstream scholarship*' can therefore also be applied to intimate care. To summarise, existing explanatory frameworks and methodologies have therefore not adequately accommodated intimate care in the social sciences or nursing literature, and it is this issue that this chapter will now turn its attention to.

## 2.13 Adopting a theoretical framework

A theoretical framework is a structure that guides research by relying on formal, established and coherent theory to provide a foundation from which to make explanations and predictions (LoBiondo-Wood and Haber, 1998). Theoretical perspectives guide the researcher, consciously or unconsciously throughout the research process and are used in research methodology, analyses and conclusions (Love, 2000). Using a theoretical framework allows researchers to align their work with a paradigm that is shared with other scholars (Love, 2000), and in this thesis, this allowed me to make a contribution towards a formalised body of knowledge.

Lawler (1991) has argued that it is possible for nursing theory to accommodate the body, but locating intimate care within nursing theory for the purposes of this thesis was problematic because this thesis was concerned with intimate care in social care settings where it was not being provided by the nursing profession. It was therefore necessary to adopt a theoretical framework from outside nursing for the study of intimate care. In this thesis, the theoretical framework has been taken from sociology, and this has provided an opportunity to develop a formal theory that was not constrained to any one profession, but that could potentially be applied across various settings within which intimate care is carried out.

This chapter has led to the constitution of an argument that an understanding of the unique social interactions between the persons giving and receiving care is important for understanding how people with severe and profound intellectual disabilities subjectively experience intimate care. This argument rests on an assumption that, despite the extent of communication difficulties faced by this group (Ware, 2003; 2004), people with severe and profound intellectual disabilities are able to interpret symbolic aspects of interaction and do have modalities for symbolic life upon which forms of sociality and mutuality can be built (Klotz, 2001). This view opposes a belief, which holds that specific linguistic skills and capabilities are necessary attributes for such understanding.

Klotz (2004) has criticised earlier anthropological studies of Edgerton (1967) and Goode (1980) who attempted to understand the life worlds of people with severe and profound intellectual disabilities, but failed to acknowledge that these people used symbolic representations. Klotz's (2001) thesis focused on the ability of people with severe and profound intellectual disabilities to communicate meaningfully using symbolic representations, which include non-verbal components of communication such as vocalisations and facial expressions.

However, Klotz's thesis, and much of the other research and literature in this area has focussed on the ability of staff to interpret intentional and non-intentional communication of people with intellectual disabilities, or on the ability of people with intellectual disabilities to understand functional communication (for example; Bradley 1998; Grove *et al*, 1999; Bradshaw, 2001; Hogg *et al*, 2001; Porter *et al*, 2001; Cummins, 2002; Ware 2003, Ware, 2004). There has been little attention paid to the ability of people with intellectual disabilities to interpret non-functional aspects of intentional and non-intentional communication or on the effect that this might have on their subjective well-being and sense of self. This present thesis extends the argument made by Klotz (2001) by suggesting that people with severe and profound intellectual disabilities are not only able to use symbolic representations to communicate, but are also able to interpret the

symbolism attached to the way that others interact and communicate with them. If it is accepted that people with severe and profound intellectual disabilities have the ability to use symbolic representations, they must also have the ability to interpret symbolic representations, because it is through interaction and interpretation that their use is learnt (Ferris-Taylor, 2004).

This argument is also founded on an understanding of communication development in 'neuro-typical' infants. Adopting a functional perspective, the stage of development that people labelled with profound and multiple learning disabilities are thought to be at has been compared to that of an infant two years of age or less (Ware, 1996). However, even at such an early stage of development, individuals are thought to be able to respond to verbal and non-verbal aspects of language and to identify whether a familiar person shows positive or negative emotion, because these abilities are thought to develop as early as in the first weeks of life (Ware, 2003; National Literacy Trust, 2007).

Furthermore, Muller and Carpendale (2004) have reviewed the literature on social behaviour in infancy and have concluded that there is evidence to suggest that in the first year of life, infants have acquired social understanding and social behaviours. For example, the ability to interpret emotional communication of their parents has been identified in infants as young as nine months old (Müller and Carpendale, 2004).

This suggests that highly developed intellectual skills may not be necessary to understand the symbolism that is attached to communication, and the term 'emotional intelligence' has been used to refer to the idea that;

*'somewhere they know and understand what is happening within and around them'* (Sinason, 1992, p214).



Therefore, even though people with profound intellectual disabilities may remain in the early stages of intellectual development throughout their lives, their psychological and emotional development may be more advanced than might at first appearances be apparent. This means that it is not possible to dismiss their ability to understand certain aspects of communication.

As recipients of intimate care;

*'people with learning disabilities are likely to interpret and assimilate overt and subliminal messages about their own bodies, who has access to them, what is done to them and consequently the roles played by other people in their lives.'* (Carnaby and Cambridge, 2006c, p182).

The interpretation made by people who have limited linguistic and intellectual capacity might therefore be made at an emotional, experiential level rather than at a cognitive level. The challenge in this thesis was to understand what interpretations care-receivers might make during intimate care, and how these interpretations might impact on their subjective experience of intimate care.

In chapter 1, section 1.3, it was argued that the communication difficulties experienced by many, if not all, people with severe and profound intellectual disabilities make it almost impossible to gain first person accounts of their experiences. This ruled out the use of particular research methods that rely on language to access the subjective 'lived experience' of participants, which includes; interviews, life histories and phenomenology (Robson, 2002; Kleiman, 2004; Klotz, 2004). Some research; including Cambridge and Carnaby's (2002) study on intimate care, has relied on proxy accounts provided by staff. However, as previously stated, Cummins (2002) has been unable to find any evidence that obtaining proxy accounts is a valid method for ascertaining the subjective well-being of people with intellectual disabilities.

An implication of these methodological difficulties was that a theoretical understanding of experience of intimate care would need to be grounded based on what could be observed. This study has therefore used methods traditionally associated with the ethnographic research tradition because ethnography has the potential to allow the researcher access to the experiences of people who are non-verbal by entering, participating and observing the social and cultural world (Klotz, 2004). The tools used for data analysis were derived from grounded theory; a research method which, also has foundations in symbolic interactionism (Denzin and Lincoln, 2000; Charmaz, 2006). A detailed account of the use of ethnography and grounded theory is provided in the next chapter, and this chapter moves on to describe symbolic interactionism which is the theoretical framework which has been used to develop a theoretical understanding of the experience of intimate care.

## **2.14 Symbolic interactionism**

Symbolic interactionism is a theoretical framework which allows the researcher to study aspects of interaction which are amenable to observation (Blumer, 1969). It is a theoretical perspective of social psychology, which stresses the symbolic nature of human interaction and the role of communication in the formation of mind, self and society (Cuff *et al*, 1998). Symbolic interactionists focus on subjective experience as a means for understanding human action and how interactions revolve around the process of reaching common understanding through the use of language and other systems of communication. Mead (1863-1931) has been recognised as the father of symbolic interactionism, although the term was originally coined after Mead's death by Blumer in 1937 (Ritzer, 1996).

Blumer was a social psychology student of Mead's who developed a formulation of symbolic interactionism based on Mead's teachings (Blumer, 1969). Blumer (1969) has argued that the influence of meaning on social behaviour is fundamental to symbolic interactionism, and his theory rests on three premises;

1. Humans act towards things based on the meaning the things have for them.
2. Meaning is derived from, or arises out of social interaction
3. Meanings are handled in and modified through an interpretive process used by the person in dealing with the things she or he encounters.

Therefore, symbolic interactionism provides a theoretical framework for understanding how intimate care might be experienced by people with severe and profound intellectual disabilities by studying the interaction that takes place with the care-giver. As already said in the previous chapter, this theoretical framework was not imposed on the data at the outset of the study, but was adopted following initial stages of data collection and analysis.

Blumer's (1969, p21) formulation of symbolic interactionism also provided a '*perspective in empirical social science*' with a clear set of methodological implications based on 'root images' which constitute a framework for study and analysis. The origin of these root images can be traced back to pragmatism and psychological behaviourism which are the two philosophical foundations of symbolic interactionism (Ritzer, 1996). This section moves on to consider the implications of these philosophies for the study of intimate care.

According to pragmatism, reality is created as we act in the world, and as we act toward the world, and the meaning of objects therefore resides in the behaviour directed toward them, and not in the objects themselves (Ritzer, 1996). Unlike the structural functionalist perspective, which stresses the idea of culture and a social system imposing structure, symbolic interactionism focuses on the role of individuals in giving meaning to social situations through their interactions with others. According to Blumer (1969), the essence of society lies in an ongoing process of action, not in a posited structure of relations. Structural features, such as culture and social systems, according to Blumer (1969) set conditions for

action but do not determine action. To apply this to the substance of this thesis, from a symbolic interactionist's perspective, intimate care is therefore a social construction that must be understood through the interactions that take place between care-giver and care-receiver.

According to Blumer (1969) when individuals join their line of action with others, group or joint action emerges and such 'interlinkage of action' allows symbolic interactionism to account for the collective action that is evident in society. Mead also developed the concept of the 'game stage', which refers to how individuals learn to take the attitude of other people and how they learn to function in organised groups. Out of the concept of the 'game stage', Mead postulated the concept of the 'generalised other', which refers to the collective attitude of an entire community or society. The generalised other allows individuals to see themselves as a participant in their society engaging in shared meanings with others. This is important for theories about social control, and in the context of the present thesis it has implications for understanding the actions of care-givers during intimate care and how they come to assign meanings to intimate care and to care-receivers.

The notion of a generalised other might suggest that care-givers learn how to carry out intimate care and how to interact with people with severe and profound intellectual disabilities from observing and interacting with other staff. According to symbolic interactionism, the actions of care-givers are not determined by a social structure, but social structure is a framework within which individuals develop their actions.

This suggests that the way that intimate care is carried out is a result of care-givers constructing their actions by interpreting the meaning of the objects they are acting towards. 'Intimate care', 'care-givers' and 'care-receivers' are considered to be objects, and an object's meaning for a person arises out of the way others act towards the object, and it is the meaning of the object that also

determines action. Therefore, in this thesis it was important to understand the meaning that 'intimate care' and 'the care-receiver' had for the care-giver, as these meanings influenced how they would act towards the care-receiver in the context of intimate care.

Symbolic interactionism is also rooted in the philosophical perspective of psychological behaviourism, which holds that there is more to behaviour than what can be observed and in symbolic interactionism; 'the act' is therefore comprised of both overt and covert aspects of human action. Symbolic interactionism suggests that the covert aspects of interaction can be revealed by understanding the symbolism that is attached to those interactions. This implies that the meaning of intimate care to care-givers can be understood by examining the symbolism attached to the way that they carry it out. Similarly, the meaning that care-givers assign to care-receivers can also be understood by examining the symbolism that is attached to the way that they act towards them.

Ontologically, Mead's symbolic interactionist evolutionary model asserts that mind, self, symbol and institution are co-evolutionary emergent aspects of social acts and that symbolic communication is a key to this emergence (Fararo, 2001). The self is therefore a process, rather than a structure that develops through interaction and is one of four co-emergent aspects of social acts. Self and other are sustained by interactive relations, and it is within and through these relations that concepts of self and other evolve (Müller and Carpendale 2004). Therefore, we see ourselves as others see us, and in symbolic interactionism the way others see us is called the 'ascribed status'.

Whereas cognitive theorists, such as Piaget, focused on humans as being biologically and psychologically constituted (Carpendale and Müller, 2004), symbolic interactionism sees them as socially constituted (Mead, 1934; Cuff *et al*, 1998). The process by which society influences the individual has been described as 'internalisation', and this involves importing material from other

persons and social institutions into the individual's thinking and affective processes (Carpendale and Müller, 2004). Carnaby and Cambridge (2006c) have also pointed out that the experience of being dependent on others for intimate care is likely to impact on the development of self. Through symbolic interactionism, individuals adopt a view of themselves that is a composite of the evaluation made of them by others. This is important because it suggests that people with intellectual disabilities may construct their self-concept through the interaction they have with people around them.

Within the theoretical framework of symbolic interactionism, a researcher attempts to comprehend the participant's world through a sharing of interpretations (Chenitz and Swanson, 1986). For the purposes of this thesis, as already discussed, people with severe and profound intellectual disabilities were not able to act as direct informants and this presented a greater restriction on establishing shared interpretations, than research that involves people who are able to act as direct informants. It was therefore necessary to consider a range of possible interpretations, and this was achieved using a collection of analytic tools, which will be described in chapter 6. Some of these tools were used to enhance 'sympathetic introspection', a technique from symbolic interactionism which involves the researcher analysing a participant's consciousness by putting themselves in the place of the participant. Mead has emphasised the human ability to 'take the role of the other'; imagining how others might feel and behave in certain circumstances, and accepting that humans have this ability is important for the validity of this study.

Human beings are also objects of their own actions and possess a self that allows them to communicate and make indications to the self. This suggests that the way that care-givers interact during intimate care is a result of the indications that they make to their self. Through self indication, one can interpret the world and construct one's own actions, and this means that we cannot understand one person's actions until we can 'get inside the defining process of the actor'

(Blumer, 1969, p16). This means that in order to understand the way that staff carry out intimate care, it is necessary to understand the meanings that they attach to it. The ability of individuals to communicate with their self also enables them to adopt an 'outside perspective' and to engage in role-taking, where they put themselves in the position of another person to produce knowledge about another person's principles, values and sensitivities. This suggests that through the method of participant observation and partaking in the intellectual activity of 'role-taking' it may be possible to gain an insight into how people with severe and profound intellectual disabilities experience intimate care. Furthermore, the ability of individuals to think by communicating with their self enables researchers to adopt a reflexive approach to their study. Reflexivity was pivotal to the rigour of this research and is discussed in detail in chapter 3, section 3.4.

To summarise, this thesis uses the theory of symbolic interactionism as a framework for analysing how people with severe and profound intellectual disabilities interpret the symbolism attached to the intentional and non-intentional aspects of the interaction that takes place with their care-giver within the context of intimate care. The framework has been used to produce a theoretical explanation for care-givers interaction based on the meaning that they attach to intimate care and the people that they are acting toward.

This chapter also argues that locating the research question within the theoretical framework of symbolic interactionism, provided a pathway for determining how this present research problem was addressed, and precisely which questions needed to be asked. The research questions were not pre-imposed but evolved throughout the study and were constructed in line with symbolic interactionism. The types of questions asked, within this theoretical framework, concern actions, interactions and their meanings (Blumer, 1969).

## 2.15 Research questions

The research set out with the research question;

*How do adults with severe and profound intellectual disabilities experience intimate care?*

However, following preliminary stages of the inquiry it was found that what is important to people on the receiving end of care is their feelings and subjective reaction to the way that care is carried out, and specifically the interaction that takes place with the care-giver. Therefore, the research questions were progressively focussed in line with the theoretical framework of symbolic interactionism.

*How does the symbolism that is attached to the way that intimate care is carried out affect the way that it is experienced<sup>1</sup>?*

- How do carers interact with people with severe and profound intellectual disabilities during intimate care?
- What do carers do when providing intimate care?
- How do carers and people with severe and profound intellectual disabilities interact during intimate care?
- What meaning does intimate care have for carers?
- What meaning does intimate care have for people with severe and profound intellectual disabilities?
- How are meanings developed?

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<sup>1</sup> This thesis is concerned with a specific aspect of experience, which is the care-receiver's feelings and subjective reaction to intimate care, rather than other dimensions such as physical or sensory experience.



## 2.16 Summary and conclusion

This chapter has argued that there has been a lack of research on the intimate care experiences of people with severe and profound intellectual disabilities, and also that a failure by previous researchers and commentators to locate intimate care within a theoretical framework has meant that understanding this area of life has been poor. Furthermore, the wider literature on the lives of people with severe and profound intellectual disabilities has suggested that understanding interaction is a key to understanding how this group experience intimate care. This study has therefore been located within a theoretical framework of symbolic interactionism. The study specifically aimed to address the research question 'how do adults with severe and profound intellectual disabilities experience intimate care?' However, the development of a formal theory in line with symbolic interactionism meant that the study may have relevance for other groups who also depend on others to provide their intimate care, and therefore experience intimate care as a social interaction. This thesis may also have relevance to other activities that involve care being provided by one person to another. The use of a theoretical framework has implications for the methodology that is used in research (LoBiondo-Wood and Haber, 1998) and the next chapter will explore this issue along with the wider philosophical and political influences on research design.

## Chapter 3: Influences on design

Qualitative researchers '*study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them*' (Denzin and Lincoln, 2005, p3).

### 3.0 Introduction

The previous chapter discussed the role of symbolic interactionism as a theoretical framework within which this present research has been carried out. An implication of symbolic interactionism is that the phenomenon to be examined must be studied within its natural context (Blumer, 1969). Symbolic interactionism rests on epistemological and ontological assumptions that are associated with the philosophy of naturalism, and research that is conducted within this theoretical framework generally uses qualitative research approaches.

However, a dominant view in western society has been that research is only legitimate and valuable if it has been conducted using quantitative methods which are associated with a positivist philosophy (Robson, 2002). The first part of this chapter therefore explains why a positivist methodology was not appropriate for the research question addressed in this thesis, and why the use of qualitative methods was necessary for producing legitimate and valuable research findings. The chapter goes on to describe the specific methodological approaches of ethnography and grounded theory that have been used in this study. The design of the methodology was also influenced by political concerns associated with involving people with disabilities in research, and the final section of this chapter is devoted to considering these issues, with particular attention paid to the implications of the emancipatory, participatory and inclusive research paradigms.

This chapter commences by examining the impact of philosophical ideas about the nature of truth and reality on the way in which research has been carried out over the last century.

### **3.1 Research and philosophy**

The nature of reality and the nature of knowledge have long been debated by philosophers. Philosophical ideas about what constitutes 'truth' and 'reality' and how the world can be understood have influenced the way in which the human race has sought to study and understand the world. Research methodologies have been guided by beliefs about the world and how the world should be understood and studied (Denzin and Lincoln, 2005). Kuhn (1970) has suggested that beliefs about ontology (the nature of reality), epistemology (the relationship between the inquirer and knowledge) and methodology (how we gain knowledge of the world) constitute a 'paradigm'. The next section of this chapter traces some of the major developments in research methodology, and considers the implications of various approaches for the study of intimate care in the lives of people with severe and profound intellectual disabilities.

#### **3.1.1 Positivism**

Positivism has been associated with 'realism', which is a belief in an objective, external reality existing independently of human thought (Crossan, 2003). Positivists are deterministic, believing that the world operates by universal laws of cause and effect, which have the status of 'truth', and the purpose of science is to uncover these laws through manipulation and empirical observation (Smith, 1998).

Within a positivist paradigm, the ideas of Popper (1978) have been influential in the development of quantitative research methods, such as the experimental method and the randomised control design, which over subsequent decades,

became the 'gold standard' of quality research (Robson, 2002). The idea that the same quantitative methodological principles that have been applied to the natural sciences should also be applied to study the social world has been called the 'received view' of science, and dominated social research until the end of the twentieth century (Oliver, 1992; Smith, 1998).

However, Ayer (1936/1990), Wright Mills (1959) and Hughes (1990) have argued that the social world does not operate by universal laws of cause and effect, and therefore positivist methods should not be used to study it. An implication of choosing to embrace a positivist paradigm, in this present study, would be that intimate care would need to be reduced to observable and measurable variables in order to study it. The previous chapter has shown that intimate care is a complex phenomenon involving physical and social interactions between the care receiver and the care giver. Therefore, although quantitative methods could be used to study particular, quantifiable aspects of care, such as how long intimate care activities took to be completed, such methods would be of little use for understanding the subjective experience of intimate care.

Furthermore there are serious ethical implications with imposing experimental conditions on human subjects (Smith, 1975) and these issues are particularly relevant for research involving people who are unable to give informed consent (DoH, 2001b). The ethical issues of conducting research on intimate areas of life are discussed in detail in chapter 5, section 5.4, and so are not rehearsed again here.

In academia, awareness of the limitations of positivism for social inquiry has led to a shift towards acceptance of the contribution that naturalism and qualitative approaches can make towards our knowledge and understanding of the social world (Hammersley and Atkinson, 1995; Robson, 2002). This issue is not about which approach to research is the best *per se*, but it is about 'methodological coherence', which means choosing the most appropriate approach for a

particular research question (Morse *et al*, 2002). Having concluded that the use of positivist research was not appropriate for the research questions addressed in this thesis, this chapter now moves on to describe the contribution that naturalism has made to research methodology.

### 3.1.2 Naturalism

Historically, naturalism can be traced back to the philosophical ideas of Droysen, Dilthey, Simmel and Max Weber (Von Wright, 1978). From the perspective of naturalism, the aim of social research is to study the social world in its natural state, rather than in the artificial settings that experimental conditions impose (Robson, 2002). Reality is therefore seen to exist in the empirical world, not in the methods used to study it (Blumer, 1969).

Both positivism and naturalism share a commitment to understanding social phenomena as having a pre-given existence that can be studied independently of the researcher (Hammersley and Atkinson, 1995). However, from a naturalistic perspective, social phenomena are fundamentally different to natural phenomena, and the view that truths can be established by the methods of natural science is rejected (Wright Mills, 1959). Human experience, which might include the subjective experience of intimate care, is not beyond the realms of scientific inquiry, but the methods that are required to study it are different to those used in positivist research.

Naturalism is consistent with a symbolic interactionist perspective which holds that social phenomena cannot be understood as simple causal relationships because human actions are based on meanings, intentions, beliefs and values (Hammersley and Atkinson, 1995). Although a commonality between the natural and social sciences is that both share a purpose of uncovering patterns and regularities, the epistemological difference is that in the natural sciences they are 'law-like' regularities, whereas in the social sciences they are 'rule-following' ones

(Winch, 1990). 'Rule-following' regularities are socially constructed and an understanding of these rules cannot be achieved using reductionist quantitative methods because they are thought to be too simplistic (Denzin, 1971). In order to understand 'rule-following' regularities, it is necessary to study the way that individuals and societies learn and interpret rules. In relation to this present study, this suggests that it may be possible to search for regularities and patterns, but also that the complexity and variability in these patterns must be explored and understood.

Naturalism is associated with the use of qualitative methods, and their advantage for this research is that they can allow for abstract concepts such as 'meanings' and 'experiences' to be studied. In chapter 2, section 2.13, a rationale was given for the rejection of particular qualitative methods for the purposes of this study, and how a decision was made to use methods from the research traditions of ethnography and grounded theory. This chapter now moves on to discuss these methodological approaches in more detail.

## 3.2 Ethnography

Ethnography is a naturalistic methodological approach that allows the researcher to enter into, and participate in, a social setting. Ethnography is based on the epistemological assumption that the nature of reality can be understood by considering how people react within the environment and in relation to each other. Leininger (1985) has described ethnography as;

*'The systematic process of observing, detailing, describing, documenting, and analysing the lifeways or particular patterns of a culture (or subculture), in order to grasp the lifeways or patterns of the people in their familiar environment' (Leininger, 1985, p125).*

Ethnography is an approach that has developed from the field of anthropology, and its pioneers have included Malinowski (1922), Boas (1924), and Mead (1929). These anthropologists visited foreign places where they lived for a prolonged period of time, participating and observing cultural groups, asking questions and collecting cultural artefacts (Fetterman, 1998). In these studies, ethnography was underpinned by an ontological position of 'realism' which implies that it is possible to have direct access to reality, and to study the world objectively. It was thought that ethnography allowed the researcher to 'immerse' themselves in an unfamiliar culture to get as close to the reality of the people being studied as possible (Hammersley, 1992). Because of its reliance on participant observation, ethnography has been regarded as a method ideally suited to non-literate cultures (Hammersley and Atkinson, 1995). Arguably, this makes it ideally suited for studying the experiences of non-verbal people with severe and profound intellectual disabilities.

However, an ethnographic study of intimate care in the lives of people with severe and profound intellectual disabilities could not share all of the features of traditional, anthropological ethnography. This is because it was not practical to live with the people who would be studied and having worked in residential homes for people with intellectual disabilities, the setting would not be 'foreign' or unfamiliar. Furthermore, the study would involve examining just one aspect of daily life; intimate care.

Kleinman (1992) has noted that studies related to care have often dealt with a specific spectrum of experience, and suggested that these studies could be described as a 'mini-ethnographies'. Such studies have usually been carried out in cultures that are familiar to the researcher, and have consequently been referred to as 'urban ethnographies' (Cuff *et al* 1998; Hammersley and Atkinson, 1995). It has been argued that these kinds of studies may undercut a purpose of ethnography which is contextual analysis (Savage, 2000). However, the use of anthropological methods for the study of specific sociological phenomena within

the researcher's own culture has been upheld by esteemed researchers including Hughes, Becker, Goffman and Strauss.

The value of ethnographic research has been the subject of much criticism as a result of its original commitment to realism and to a belief that social research should be value free (Blumer, 1969; Hammersley, 1992). An extreme relativist ontological view, which is shared by social constructivists, is that reality, and therefore truth, exists in the minds of people, not in the empirical world (Guba and Lincoln, 1981). Epistemologically, relativism therefore assumes that;

*'knowledge is socially constructed and the product of a particular historical context within which it is located'* (Oliver, 1992, p106).

According to relativism, the ethnographer's account provides just one version or construction of reality, and therefore cannot be generalised to other cases (Crossan, 2003; Kleine, 1990). A current view in social research involves adopting a third way between positivism and relativism, which has been referred to as 'subtle realism' or 'critical realism' (Hammersley, 1992; Robson, 2002). The epistemological position that has underpinned the methodology used in this thesis is Hammersley and Atkinson's (1995) conception of critical realism.

### **3.3 Critical realism**

Hammersley (1992) has argued that neither 'naïve realism' nor relativism has provided adequate accounts as to the nature of knowledge and that the value of ethnographic research can be understood if the reflexive nature of all social research is accepted and embraced. According to Hammersley and Atkinson (1995), we cannot escape the social world in order to study it, but there is a shared reality and the closer research gets to that reality the more likely conclusions will be valid.



Critical realism refers to the epistemological position that knowledge can be regarded as true by virtue of the fact that it corresponds to the phenomena it is intended to represent. This position accepts the existence of an external, independent reality and that it is possible to investigate 'independent knowable knowledge', whilst recognising that this does not necessarily result in a direct awareness of reality (Hammersley, 1992). In line with constructivism, critical realism therefore accepts that we each construct our view of the world based on our unique perceptions of it, but this does not mean that we are unable to access and understand one another's constructions (Trochim, 2005). It does, however, mean that all measurement and observation is fallible and imperfect, and hence must be interpreted 'critically'. This implies that it is possible to study intimate care through ethnographic methods of participant observation and interview, but that the findings made from such study will be influenced by the biography and personal perspectives of the researcher, which must therefore be taken into account when evaluating the research.

Critical realism assumes that interpretation is at the heart of research and that research is driven by the researcher's personal values, histories and interests (Koch and Harrington, 1998). This type of research can be described as interpretivist, and is a form of inquiry in which the goal of research is to understand the subjective meanings of personal experiences whilst accepting that meanings are varied and multiple (Smith, 1975; Ferguson *et al*, 1992).

An implication of the interpretive nature of research is that ethnographers must be vigilant about methodological causes of error. A view taken by Scholte (1974) was that anthropology is incapable of producing value free studies of cultures, and therefore ethnographers should study their ideologies and their reasons for carrying out the research. Furthermore Strauss and Corbin (1998) have argued that it is not possible for researchers to have an 'empty head' and divorce themselves from what they know, but it is possible for them to be open minded. Although the effects of the researcher on the researched, or the

constructive nature of the findings cannot be eradicated, it is possible for researchers to monitor these effects, and to use this accumulated knowledge, rather than dispensing with it (Hammersley and Atkinson, 1995; Strauss and Corbin, 1998). Hammersley and Atkinson (1995) have proposed that this can be achieved by adopting a reflexive approach to research.

### 3.4 Researcher's role and reflexivity

An influence of positivism has been the promotion of objectivity through scientific detachment, and this has led to the idea that the researcher should take on the role of a '*detached, impartial observer*' (Northway, 2000). In contrast, research that is carried out in line with critical realism acknowledges that it is not possible to separate the researcher from the research because '*researchers both influence and are influenced by the process of engaging in research*' (Northway, 2000, p391). According to Davis (1973), positivists regard distance as a passageway to gaining truthful knowledge, whereas critical realists view it as a barrier.

In phenomenology the researcher uses a technique known as 'bracketing' to separate personal views and biases from the phenomenon being studied. However, according to Hammersley and Atkinson (1995), it is an existential fact that the researcher is part of the social world, and therefore it is impossible for them to escape the social world in order to study it. The effects of the researcher and how people react to the researcher can be illuminating and therefore given the status of data and treated as integral to analysis through the method of reflexivity. Reflexivity also involves going beyond setting aside personal beliefs and requires their integration and application in the development of a new understanding of the phenomenon (Lamb and Huttlinger, 1989).

Reflexivity requires a researcher to make their personal assumptions, values, biases and prejudices explicit and subject them to critical examination (Northway,

2000). For this reason a reflexive approach has been taken throughout this research. Reflexivity includes reflection on the products of the researcher's involvement, attempting to understand what effects they have had on the behaviour of participants and critical reflection of the researcher's personal motivation for carrying out the research (Hammersley, 1992; Hammersley and Atkinson, 1995).

The place of diaries and confessionals, including a personal biography and reflexive account in ethnographic texts, is imperative to enable the reader to judge for themselves the truthfulness of what they have read (Lamb and Huttlinger, 1989; Kleine, 1990). Reflexivity also requires the researcher to reflect critically on the impact of their professional values, and this has specific implications for nurse researchers.

The profession of nursing, and more specifically learning disability nursing, is associated with a body of theoretical and professional ideas. Through the course of training and practice, nurses are indoctrinated into the values and principles of their profession at both a conscious and unconscious level (Becker, 1961; Melia, 1987). Nurse researchers must therefore examine the beliefs and values that are associated with the culture of their profession and make these explicit in order to understand what effect this may have on the research process (Lamb and Huttlinger, 1989). For this reason, within the reflexive account that can be found in appendix 2, the various influences that have informed my particular academic perspective are discussed in an open manner.

Rioux (1997) and Northway (2000) have also argued there are value judgements and normative standards hidden in empirical research which the researcher must be mindful of, and this is particularly important with research involving people with severe and profound intellectual disabilities who are amongst the most marginalised and vulnerable group of people. This involves uncovering elements

of various formulations and approaches to disability, and the world views that underlie them.

Maintaining an on-going reflexive approach throughout the entire study involved keeping two journals; a methodological journal to record ideas, decisions, problems and questions and a personal journal to record thoughts and feelings about the research process and about being a PhD student. Excerpts from these journals have been included in this thesis where they have been pertinent to, or illustrate a point that is being made, or where they are important for understanding decisions that have been made. These excerpts are thus treated as a source of data and enable any reader of this thesis to assess how personal biases might have influenced the arguments that have been made.

The value of including reflexive accounts in ethnographic writing is based on the assumption that through language we can access a shared understanding of subjective meaning of actions, a view that is congruent with symbolic interactionism. However, post-structuralism and the work of Foucault was based on anti-realist ideas and recognised that the language used by ethnographers is not a transparent medium which allows us to see reality through it, but rather a construction of reality that draws on many of the rhetorical strategies, in a similar way to those used in the work of journalists and novelists (Foucault, 1969).

When ethnographers write, they are aware that they are writing for a particular audience and endeavor to influence the audience through their writing. I was primarily writing this present thesis with the PhD examiners in mind, and this meant writing for an audience who would be assessing this work to see if it met the requirements of PhD. These requirements are that the thesis makes an original contribution to knowledge and shows that the PhD candidate has competence in research processes, and has mastery of a body of knowledge (Phillips and Pugh, 2000). The ethnographer is not a strict empiricist, but a rhetorician who attempts to construct a text that will be effective (Kleine, 1990),

and this might suggest that a PhD thesis is written to be effective in showing competence, rather than, for example to be effective in conveying any political or personal messages. However, there was a desire for this research to improve intimate care by understanding the experience of it better.

Hammersley and Atkinson (1995) have accepted that because ethnographers construct a view of the world, the ethnographic text does not provide a direct mirror of reality. According to Hammersley and Atkinson (1995) the goal of ethnography should therefore not be to reproduce reality but to represent it. This view has important implications for this research. If the idea is accepted that ethnographic accounts are a representation or construction of reality, it could also be accepted that although it may not be possible to reproduce the reality of people with severe and profound intellectual disabilities, it may be possible to represent it. Through critical realism and the use of a reflexive approach, it is therefore accepted that the representation of the intimate care experiences of people with severe and profound intellectual disabilities made in this thesis, is just one representation, but that it can, and does, make a valuable contribution to knowledge and understanding.

During the initial stages of analysis, it emerged that there was potential to move beyond the description and representation that is characteristic of ethnographic research towards the development of a theoretical explanation for the experience of intimate care. It was at this point that a decision was made to adopt tools from grounded theory to continue with the analysis of the data. This chapter now moves on to discuss the role of theory in research that is carried out within the interpretive paradigm that has been used in this thesis.

### **3.5 The role of theory: towards a grounded theory**

The role of theory in ethnographic research has been contentious. Traditional anthropologists used ethnographic methods in an aim to produce what Geertz

(1973) has called a 'thick description' of the culture they were studying.

Description, rather than explanation has traditionally been the primary goal of ethnography (Spradley, 1979) and consequently, ethnography has been seen as an art or craft that lacks systematic methods of analysis. However, Wright Mills (1959) has argued that social scientists are generally interested not just with description, but also with analysis and the development of theory.

Glaser and Strauss (1967, p3) have defined theory as '*a strategy for handling data in research, providing modes of conceptualization for describing and explaining*'. Glaser and Straus (1967), Denzin (1978), Spradley (1979;1980) Hammersley and Atkinson (1995), Clarke (2005) and Charmaz (2006) have argued that the development of theoretical propositions in ethnographic studies is possible. Positivist objections to this argument have often been founded on the belief that ethnography has lacked a systematic methodology. Attempts have therefore been made to develop systematic methods of data collection and analysis and this has sometimes involved taking approaches from other research traditions and applying them to data that has been collected through ethnographic methods (Spradley, 1979; Hammersley and Atkinson, 1985; Charmaz, 2006).

The theory that develops from the generation of concepts in ethnographic research, in Hammersley and Atkinson's (1995) view, should be tested using a comparative method. The experiment is generally considered to be the most powerful of comparative methods (Robson, 2002). However, this chapter has argued that the experiment was not a viable method on ethical or pragmatic grounds for this study. Furthermore, as so little was known about intimate care in the lives of people with severe and profound intellectual disabilities, a deductive approach to research involving the experimental testing of a preconceived theory was not appropriate. Grounded theory offers an alternative, inductive approach that can be used to build theory from data collected using ethnographic methods. It is coherent with the philosophy of this research because it is underpinned by a

shared epistemology, that is derived from symbolic interactionism, and both ethnography and grounded theory place importance on openness and progressive focusing (Denzin and Lincoln, 2000; Charmaz, 2006).

Glaser and Strauss (1967) were the pioneers of grounded theory, but later parted ways because of differences in opinion on certain methodological aspects of the research approach. Strauss took a more structured approach, stressing the role of the constant comparative technique, whereas Glaser stressed the importance of 'theoretical sensitivity' for the emergence of theory. Grounded theory has subsequently been interpreted in various ways and this has provided qualitative researchers with a selection of tools and techniques to choose from (Strauss and Corbin, 1998; Clarke, 2005; Charmaz, 2006). The approach used in this study was consistent with the methodological approach and epistemological and ontological assumptions of Strauss and Corbin (1998) and Charmaz (2006), but the tools of analysis have been taken from a variety of sources which will be described later in chapter 6.

The methods of analysis used in grounded theory are considered to be inductive because the themes are not imposed on the data, but rather are identified directly from the data. The researcher does not therefore know what themes will be identified prior to data collection and it was only after initial themes were identified that it became clear that this study fitted in with the theoretical framework of symbolic interactionism. Themes, or concepts can arise out of searching the data for patterns, relating data to common sense knowledge or previous theory, and they can also be borrowed from other disciplines.

These concepts can be differentiated into two types which Blumer (1954) referred to as 'definitive concepts' and 'sensitising concepts'. Definitive concepts '*provide prescriptions of what to see*', whereas sensitising concepts '*suggest directions along which to look*' (Blumer, 1954, p7). Hammersley and Atkinson (1995, p180) have called these sensitising concepts '*the germ of the emerging theory*'. The

ethnographer moves between sensitising concepts and real world observations in order to adapt the concept to 'fit' all observations and to develop theoretical propositions (Denzin, 1971). In this way, according to Bulmer (1984) (not to be confused with Blumer), the development of sensitising concepts allows the ethnographer to be faithful to the empirical world. Therefore, the value of using a top-down approach to generate theory is that the emerging theory is more likely to connect with the empirical world (Hammersley and Atkinson, 1995). This is a view that connects with pragmatism, which is a branch of philosophy that proposes that something is true to the extent that it corresponds to reality.

Just as with positivist research, qualitative researchers should be intentionally critical and test theories rigorously (Denzin, 1971; Crossan, 2003). The methods that have been used to increase the rigor of this present study and the validity and reliability of analysis will be discussed in chapter 6, section 6.8. One of these methods involved searching for negative cases, and the necessity of searching for cases which disprove a hypothesis to increase the validity of the theory is shared with Popper's (1978) idea that hypotheses which stand up to falsification are more likely to be valid. Smith (1998) has therefore argued that Popper's falsification can be seen as an attitude to research, as well as a set of methodological procedures that can be applied to qualitative research.

So far, this chapter has shown how philosophy has been influential in determining the use of a qualitative methodological approach using methods of ethnography and tools of data analysis from grounded theory in this research. In addition, political debates influence ideas about how research should be conducted, and this chapter now moves on to explain how these have impacted on the design of this research methodology.



### 3.6 Political influences on research

This section discusses literature which has examined political ideas about the relationship between research and the researched, and the implications of this for involving people with severe and profound intellectual disabilities in research. Recent years have seen developments in a consumer oriented focus in research and this has been influenced by the 'disability movement' as well as the wider political agenda of public participation. The 1990 NHS and Community Care Act was one of the driving forces towards the inclusion of people with intellectual disabilities in research (Ward, 1994; Gilbert, 2004), and the need for consumer inclusion in research was reinforced by the NHS Plan (DoH, 2000b) and the Research Governance Framework for Health and Social Care (DoH, 2005).

Proponents of the disability movement have argued that traditional research, based on medical and empirical models, has been carried out *on* rather than *with* people, and has therefore been criticised for failing to empower people with disabilities (Rioux, 1997; Kiernan, 1999; Ferguson, 2004). People with severe and profound intellectual disabilities have been at particular risk of being subjected to exploitation by the research community (MacInnes, 1999). According to Walmsley and Johnson (2003), medical and positivist research has objectified people with intellectual disabilities and pursued goals which set them apart from the rest of humanity, and often led to oppressive policies directed towards them. Examples of this have been seen in research on Intelligence Quotient (IQ) testing and on challenging behaviour (Walmsley and Johnson, 2004).

The social model of disability contrasts to the traditional, and arguably, pervasive models of disability which locate the problem of disability within the individual. The social model distinguishes impairment from disability and attributes disability to the way in which society excludes and discriminates against people with impairments (Chappell *et al*, 2001).

From a social model of disability perspective, it has been argued that research carried out within both the positivist and interpretivist paradigms has resulted in the problems people with disabilities face being attributed to their individual impairment (Oliver, 1992). This has been reflected in the way that research has focused on changing the behaviour of individuals with intellectual disabilities through programmes aimed to increase their independence, as discussed in chapter 2, section 2.5. Much of the intellectual disability research has therefore been dominated by attributing problems to the individual and trying to bring about change in the individual rather than looking at the problems people with intellectual disabilities face as a result of having to fit in with a society that devalues disability and devalues dependence.

### **3.6.1 Emancipatory and participatory research**

Oliver (1992) has argued that research which has located the problem within the individual has been irrelevant to the lives of the people being studied and has failed to improve the material circumstances and quality of life. He has called for the development of a new 'emancipatory' research paradigm based on the belief that there must be a change in the 'social relations' between the researcher and researched. By 'social relations', Oliver (1992) referred to a distinction between the 'researcher', who is believed to have special knowledge and skills which they use to exert control over the entire research process, and the relatively powerless 'researched'.

Changing the social relations of research through an emancipatory paradigm is based on three fundamental ideals; reciprocity, gain and empowerment. This involves developing trust, respect, and participation. Oliver (1992) has also argued that emancipatory research is only possible if control over funding is transferred to people with disabilities. Therefore, the material and the social relations of research need to be transferred to people with disabilities.

A problem with the application of emancipatory research to people who have severe and profound intellectual disabilities is that the paradigm is a product of critique about pre-existing research from the perspective of physically disabled people. Physically disabled people have, arguably been alienated by the way that they have been treated by researchers, but chapter 2 has shown that people with severe and profound intellectual disabilities may have experienced a different type of alienation, having been almost completely excluded from the research agenda.

Adopting a research paradigm developed by and for people with physical disabilities is therefore problematic, and Kiernan (1999) and Kellett and Nind (2001) have argued that there is no reason to believe that people with less severe disabilities are able to advocate for people with severe and profound intellectual disabilities whose;

*'aspirations, concerns, behaviours and expressions' are often 'very different, idiosyncratic, opaque and challenging to engage with'. (Klotz, 2004, p98)*

Furthermore Oliver (1992) has argued that emancipatory research can only be a reality if people decide to empower themselves. This kind of statement denies people with severe and profound intellectual disabilities who need support in all areas of their lives, from access to a debate about how disabled people can be meaningfully included in research.

The emancipatory paradigm has therefore come under criticism for failing to acknowledge diversity within disability. As a result, there have been various attempts to develop an approach which is more fully inclusive, and Kiernan (1999) has suggested that 'participatory research' offers a more practicable framework for people who have intellectual disabilities. However, it has been

argued that the differences between emancipatory and participatory research are not that clear and that they can actually be located at different points along the same continuum (Northway 2003).

Zarb (1992) has provided a distinction between emancipatory and participatory research which has been widely cited by contemporary writers; for research to be genuinely emancipatory people with disabilities must be fully empowered and must become the researchers, whereas for research to be participatory, involvement must occur at all stages.

Williams (1999) has claimed to conduct a research study in which people with intellectual disabilities were involved at all stages of planning, execution and analysis. However, Williams (1999) concluded from this endeavour, that for participants to be included they needed to have;

*'An ability to listen, to be interested in things, to think for themselves and to understand how others think'* (Williams, 1999, p51).

This suggests that participatory research may be more relevant and beneficial for people with milder intellectual disabilities who have a certain level of cognitive ability. According to Townsley (1998) people cannot meaningfully participate in research if they cannot understand it. However, an implication of the social model of disability would be that it is the responsibility of the researcher to promote understanding and to adapt the research process to allow for more meaningful inclusion.

Some funding organisations, including the Department of Health and The Joseph Rowntree Foundation, require researchers to involve people with intellectual disabilities at all stages of research. However, as Kiernan (1999) argued, this can automatically exclude people with severe and profound intellectual disabilities from research. As a result of the pressure on researchers to include

participants fully, the vast majority of research has been carried out with people who have mild intellectual disabilities (Walmsley and Johnson, 2003). This is concerning because,

*'the concept of people with learning disabilities as partners in research brings with it the danger of omission in research of those with the greatest disabilities.'* (Kellett and Nind, 2002, p51).

Researchers are therefore faced with a dilemma between conducting research with people who have severe and profound intellectual disabilities that does not meet the standards of full participation, and simply not carrying out research with this group at all. Kellett and Nind (2002) have argued that not including people with severe and profound intellectual disabilities in the research agenda should not be an option, and this is a view that I would fully agree with.

### **3.6.2 Inclusive research**

Arguably, the emancipatory and participatory paradigms do not offer a way to include people with severe and profound intellectual disabilities in research that can potentially have a positive impact on their lives. It has been argued that;

*'there is still a large group of people with learning disabilities and profound or multiple impairments where it seems unlikely that they could be meaningfully involved, even as respondents in research studies'* (Kiernan, 1999, p46).

However, I would argue that some of the principles of emancipatory and participatory research can be applied to enable people with severe and profound intellectual disabilities to be meaningfully involved in research. The view taken in this study was that it is possible to safeguard the interests of people with severe and profound intellectual disabilities and guide the researcher towards ensuring

maximum inclusion and participation using the principles of 'inclusive research' described by Walmsley and Johnson (2003).

Walmsley and Johnson (2003) have used the term 'inclusive research' to describe research that is based on the following principles;

- Research must address issues that really matter to people with intellectual disabilities, and which ultimately leads to improved lives for them
- Research needs to access and represent the views and experiences of the participants
- People with intellectual disabilities need to be treated with respect by the research community.

The difference between these principles and those outlined by the emancipatory and participatory paradigms is that the onus is on the researcher to act responsibly, rather than on the participant to demonstrate a sufficient level of cognitive and communication ability. Walmsley (2004a) has suggested that there is no one right way to conduct inclusive research, and adjustments should be made according to the topic, methodology and skills of those involved. The way in which the three principles of inclusive research outlined above have been applied to this research will now be discussed in turn.

In relation to addressing issues that matter to people with intellectual disabilities, in chapter 1, sections 1.2 and 1.3, it has been argued that it is difficult, if not impossible for many people with severe and profound intellectual disabilities to communicate what is important to them. It is therefore imperative that research efforts are focused on issues that have direct relevance to the experiences and lives of this group. Whilst little is known about what really matters to people with severe and profound intellectual disabilities, as discussed in chapter 1, section 1.4, it is known that intimate care can consume a large amount of time on a daily basis, and is therefore thought to have a significant impact on quality of life

(Ashurst, 2003; Mirfin-Veitch *et al*, 2004). Research in this area could therefore have the potential to lead to an improved quality of life, at least in one or some dimensions.

The second principle, that research needs to access and represent the views of the people being studied, is consistent with the use of an ethnographic methodological approach. It has been widely accepted that individuals with intellectual disabilities are the best authority on their own lives, experiences, feelings and views (Stalker, 1998). This implies adopting an epistemological stance, whereby people with intellectual disabilities are seen as the experts and the researcher is an inquirer whose role is to learn from these experts (Knox *et al*, 2000). From the perspective of the social model of disability, access to the experiences of people with severe and profound intellectual disabilities is an obstacle that must be overcome by adapting research methods. In the present study this demanded the need for spending prolonged time getting to know the participants before data collection, being open minded about what direction the research would take and using a reflexive approach to understand the influence of my own personal values and biases.

The third principle, which states that people with intellectual disabilities must be treated with the utmost respect, is of paramount importance. When designing the methodology for this study, consideration needed to be given to the ethical issues it raised, as is necessary for much 'real world' research (Robson, 2002). A detailed discussion of ethical issues is provided in chapter 5, but it is important at this point to highlight how they had a bearing on the choice of methodology and design of this study. A major challenge was to observe intimate care in such a way that would not disrespect the rights, privacy and dignity of the people being studied. This involved imposing minimum intrusion on the lives of the people being studied and meant that, in order to study naturally occurring interaction, intimate care needed to be studied without making changes to the normal course of daily life. In addition to maintaining good manners and being courteous at all

times, I endeavoured to ensure that the research did not inconvenience participants in any way and to be responsive to individual's non-verbal communication.

### **3.7 Summary and conclusion**

To summarise and conclude, a pragmatic approach has been taken to designing the research methodology that has been used in this study. This involved taking into consideration the sensitive nature of the research subject, as well as philosophical and political perspectives related to conducting social research with people with severe and profound intellectual disabilities. Adopting an ethnographic approach, and using the data analysis tools of grounded theory to analyse data within a symbolic interactionist theoretical framework has provided a solution to the problem of studying the experiences of people who are unable to give first person accounts. Having provided a background to, and rationale for, the methodology used, in the next chapter, this thesis is progressed by exploring the working methods that were adopted in undertaking this study.



## Chapter 4: Method

*'Methodological appropriateness rather than orthodoxy, methodological creativity rather than adherence to a paradigm, and methodological flexibility rather than conformity to a narrow set of rules' (Patton, 1990, p295).*

### 4.0 Introduction

This chapter provides a comprehensive description of the methods that have been used to collect data from two residential homes for people with intellectual disabilities. Data was collected using the traditional methods of ethnography; participant observation, semi-structured interviews and document analysis. In accordance with the philosophical assumptions underpinning this study, the method could not be completely specified prior to commencing this research, and to do so would have put constraints on the inquiry (Guba and Lincoln, 1981). The precise details of the method therefore unfolded over the duration of the study and this chapter could only be written in its entirety retrospectively. The chapter commences with a brief historical and geographical overview of the locations in which the research took place, and proceeds to provide a step by step account of the methods that were used to gain access to the settings and to collect data.

### 4.1 A note on ethics

Before health or social care research can commence, ethical approval must be received from an appropriate body (DoH, 2005; Mental Capacity Act 2005). Thames Valley University's Faculty of Health and Human Sciences Research Ethics Committee were responsible for reviewing this research and an application was duly submitted. The Chair of the Committee responded with a letter requesting further 'consideration and clarification', on a number of points.

Some of the points that were made required only more detail and clarification, but with regard to the issue of obtaining consent from people with severe and profound intellectual disabilities, the Committee required more extensive work to be carried out to develop a plan of action for how this issue would be addressed.

A plan was developed and clarification of the issues raised by the Ethics Committee was provided, and subsequently approval was granted. The local NHS Ethics Committee confirmed that it was not necessary to apply for NHS ethical approval because this research did not involve participants within NHS settings. Furthermore, in social care, at that time there was;

*'no system comparable to long established NHS Research Ethics Committees. Options for ethics review of social care research are under consideration' (DoH, 2005, p42).*

The approval of Thames Valley University's Ethics Committee was therefore sufficient for the research to proceed.

This ethical review was a valuable part of the research process because the feedback given by the Committee contributed to the quality of the ethical standards and the rigor of the procedures that have been used. The theoretical concepts that underpinned the ethical procedures used to deal with the issues of informed consent and dealing with poor, dangerous and abusive practice were integral to this research. Therefore, the whole of chapter 5 is devoted to discussing these issues.

## **4.2 Research settings**

In the county in which this research was conducted the government's programme to close the long stay National Health Service (NHS) hospitals for people with intellectual disabilities was finally completed in the 1990's. Many of the people

who lived in these hospitals were moved into smaller residential homes, which continued to be managed by the NHS. However, ownership and management of the majority of these homes was subsequently taken over by organisations in the private, not for profit and charitable sectors, with a few also owned and managed by social services. Since the 1990's, services for people with intellectual disabilities have seen a rise in the number of supported living schemes (Ryan 1998; Kinsella, 2001). However, people with more severe intellectual disabilities have been more likely to be placed in residential group homes because their support needs have been considered to be too high and too expensive for supported living services (Ryan, 1998).

The majority of adults with severe and profound intellectual disabilities have therefore either lived with their family, or in a group residential home (Mencap, 2001; Clark and Gates, 2006). I was interested in studying intimate care in residential homes, and the reasons for this are explained in chapter 1, section 1.2 and in my reflexive account in appendix 2. The methodological approach for this research was based on an interpretive paradigm using ethnographic methods of data collection, and this meant gaining access to residential group homes in order to participate and observe in everyday life. Sampling is neither statistical nor personal in qualitative research, it is theoretically grounded and involves choosing settings where the processes being studied are most likely to occur (Denzin and Lincoln, 2000; Silverman, 2001). The method of selection used in this study has been called 'purposive sampling' because it;

*'allows us to choose a case because it illustrates some feature or process in which we are interested'* (Silverman, 2001, p150).

It is acknowledged that there is a risk that there may be biases inherent in a sample selected using this approach. For example, it is possible that the residential homes selected were examples of 'better services' because by virtue of gate-keepers allowing me access to the homes, they may have thought that

the standards of care in the homes were good and therefore did not have anything to hide.

Service users were selected to participate if those closest to them believed that it was in their 'best interests' to do so. In the next chapter, in section 5.4, the notion of best interests is explored fully. One of the criteria that needed to be considered to determine best interests was how likely individuals would have been distressed by the presence of another person watching whilst their intimate care was being delivered. The people with severe and profound intellectual disabilities who participated in this research were therefore those more likely to be thought to enjoy interaction with other people, and have a positive experience of intimate care.

The impact of sampling biases is discussed in chapter 10, section 10.3, where it is concluded that the sampling strategy used has not invalidated the findings made in this thesis, or limited the extent to which the conclusions made have applicability to other settings in which intimate care is carried out.

#### **4.2.1 Locating research settings**

The initial intention was to conduct the research in three residential group homes. This number was chosen because it was thought that three homes would provide data of adequate depth and breadth to provide sufficient insight into the experience of intimate care, and also be a realistic undertaking in the amount of time that was available for this study. However, after conducting the research in two homes, the decision was made to end data collection, and the reasons for this are discussed later in this chapter.

For a setting to have been selected for this study, it must have met the inclusion criteria of being a 'residential group home' for people with intellectual disabilities. For the purposes of this research, a residential group home was defined as a

place in which at least three people with an intellectual disability lived, and where support was available twenty-four hours a day from paid social care staff. Also, at least one person who lived at the home must have had severe or profound intellectual disabilities, no formal communication, and had been dependent on paid staff to meet their intimate care needs. Some of the participants in this study had not received a formal diagnosis but their medical notes described them as having severe or profound intellectual disabilities.

A list of all the registered homes in the county was located from a Care Homes Directory, and using this in conjunction with information provided by my colleagues at the local Community Teams for People with Learning Disabilities (CTPLDs), I was able to identify the homes which might have met the inclusion criteria. Reed (1995) has argued that using professional knowledge in sample selection can enhance the meaningfulness of the findings for practice. Some of the home managers who I contacted early on provided me with contact details for other homes that might also have met the inclusion criteria. This is a recognised method of sampling known as 'snowball sampling' (Robson, 2002). Networking at conferences also resulted in the identification of a potential research setting. The combination of these sampling methods resulted in eight homes being identified as possible research settings. The names of these settings have been changed in this thesis in order to protect their privacy.

#### **4.2.2 Confidentiality and anonymity**

By law, all individuals have a right to privacy and researchers have a duty to safeguard the dignity and privacy of research participants by protecting confidentiality (Human Rights Act 1998; RCN, 2004). The Data Protection Act 1998 has also placed an obligation on researchers to ensure the safe storage and disposal of data. In accordance, field notes, journals and consent forms and computer files were all stored in a locked filing cabinet.

It is probably more accurate to say that research has protected the anonymity of participants, rather than their confidentiality because findings have been shared, but their source has remained anonymous. The anonymity of all participants was protected, as far as possible, by ensuring that neither the names of the participants, nor the identities of the homes in which they lived or worked could be recognised through any of my written work. Therefore, throughout this thesis the names of all participants and research settings have been changed. The only time that anonymity and confidentiality would have been broken would have been in the event that I observed, or suspected illegal or abusive activity, and this exception was made clear in an Information Sheet that was given to staff participants (see appendix 7).

However, Lofland and Lofland (1984) have recognised that anonymity in naturalistic research is a matter of degree. It is possible that people might have found out where I was conducting my research and this could have compromised the anonymity of reports that have subsequently been written and published. I tried to minimise this risk by avoiding telling people where my research was located, or why I was visiting the home. For example, during one of my field visits, a colleague of old visited one of the research settings for a meeting with the staff team whilst I was present. She was naturally curious about why I was there, so rather than telling her that the home were participating in my research, I told her that I was visiting in my capacity as a member of the university teaching staff.

I also encouraged participants to avoid telling other people about the research. However, it was not possible to guarantee that they took my advice. Therefore the potential for participants to violate anonymity was an unavoidable consequence of conducting research in a 'closed setting', where undertaking research covertly was not an option, for the practical and ethical reasons that will be discussed next, and also in section 5.7 of the following chapter.

### 4.2.3 Selection of research settings and gaining access

Within the social research literature, a distinction has been made between 'open' and 'closed' research settings (Lofland and Lofland 1984; Hammersley and Atkinson, 1995). Open settings are public places that can be accessed without the need to gain special permission. Residential services fall into the category of 'closed settings' because they are private, formal establishments for which permission must be granted before entering. Gaining access to closed settings for the purposes of research involves locating a 'gatekeeper' who can facilitate entry to that setting (Hammersley and Atkinson, 1995). The manager of a residential group home is usually the person who has immediate responsibility for the running of the home, and was therefore identified as 'the gatekeeper'.

Out of the eight homes identified as potential settings, the first home I made contact with was Fir Tree House. I chose to make contact with Fir Tree House first because I had already worked there whilst on placement as a student nurse, and was therefore confident that the manager (Sally) would agree to see me. Using '*preexisting relations of trust to remove barriers to entrance*' is a strategy for gaining access that has been endorsed by Lofland and Lofland (1984).

After making contact by telephone, I met with Sally to explain the purpose of my research and what participation would involve. This included giving an account of the processes that would be put in place to protect the rights and well-being of the participants, and these are described at length in the following chapter. Sally pointed out that little attention had been paid to intimate care in the organisation's training programmes and was keen for Fir Tree House to participate because she thought the research could be valuable for improving practice, and also that my involvement could provide other benefits, both for service users and staff. I urged Sally to consult care staff before making a decision, because their willingness to participate was essential and they would be required to give informed consent on an individual basis. Sally discussed my proposal in their

next staff meeting and reported that staff were receptive to the idea of participating.

Fir Tree House was run by an independent care provider, and in the absence of clear guidelines on gaining permission for research in such settings, permission was sought from the service provider. Lofland and Lofland (1984) have suggested that the production of a brief and straightforward account of the research proposal can help to gain initial access to a setting. Accordingly, Sally was provided with an 'Information Sheet for Service Providers' (see appendix 5), to give to her line manager. The information included a description of the purpose of the research, what would be involved, and also addressed some of the ethical concerns that service providers might have raised. After receiving this information, Sally told me that the service provider had given permission for the research to proceed, and this approval was confirmed in writing.

When selecting a second research setting, it was important that the home was somewhere that I had not worked at before, in order to offset any biases that may have resulted from conducting research in a familiar setting. Conducting research in familiar settings can have both advantages and disadvantages (Bonner and Tolhurst, 2002). Traditional ethnography requires the researcher to treat familiar cultures as 'anthropologically strange' (Whyte, 1955). A potential disadvantage of conducting research in familiar settings is that can be more difficult to see the 'strange in the familiar'.

Morse and Field (1996) have suggested that nurses who work in settings they are familiar with may have unconsciously incorporated the values of the group to be studied. Arguably, this could make it difficult to 'see what is really going on' because the setting is so familiar and normative that the details of every day events are beyond the researcher's awareness.



On the other hand, Shutz (1994) has argued that an advantage of conducting research in a familiar culture is that the researcher is able to recognise valuable data and to know when and where to look to collect the data that they need. It was therefore valuable to conduct this research in both a familiar and unfamiliar setting. However;

*'Even when he or she is researching a familiar group or setting, the participant observer is required to treat this as anthropologically strange...'*  
(Hammersley and Atkinson, 1995, p9).

In terms of triangulation, a method for enhancing rigour which is described in chapter 6, section 6.8.1, it was also important that I collected data in homes which were owned by different service providers. If the findings made in one place repeated what had been found at the other, it would suggest they were not just an artefact of the way that one particular service provider operated but might have relevance to other settings.

In total, I met with the managers of five different homes during the search for a second research setting. In principle, they were all enthusiastic about participating in the research. However, at one home, some of the service user's family members were concerned that the research may cause an increase in challenging behaviour, and so the manager had to decline. Out of the remaining four homes, Primrose Cottage was selected because it met the inclusion criteria, and because of pragmatic reasons, such as it being in close proximity to my own home, and the manager, and service provider being prompt in granting approval for the research to go ahead.

Both Fir Tree House and Primrose Cottage required a copy of my Criminal Records Bureau (CRB) check, which I was able to supply along with evidence of my registration as a PhD student, and confirmation of Ethics Committee approval. Profiles of these homes can be found in appendix 4.

Once access had been granted, an 'Action Plan' was drawn up which listed all of the tasks that needed to be completed before I could commence observations (see appendices 11 and 12). The first task was to gain consent from participants and as explained earlier in this chapter, the methods for gaining consent will be described in chapter 5.

### 4.3 Participants

In total, two service users and seven staff from Fir Tree House, and four service users and ten staff from Primrose Cottage participated in this research. These people will be referred to throughout this thesis by a pseudonym in order to maintain anonymity as far as possible within the constraints already acknowledged (see figure 4.1). The positions of staff within the homes have been illustrated in staff organisational charts, which can be found in appendix 4.

**Figure 4.1 Pseudonyms of staff and service users**

	<b>Service Users</b>	<b>Staff</b>
<b>Fir Tree House</b>	Simon Barry	Sally James Denise Faye Joan Sharon Adrian
<b>Primrose Cottage</b>	Mary Beth David Elaine	Frank Jenny Lorraine Gemma Bella Josie Sarah Rita Lisa Caroline

Lofland and Lofland (1984) have suggested that the absence of real names helps to focus on generalisable patterns emerging from the data and to avoid telling a 'juicy' human interest story. This suggestion is consistent with the goal of ethnographic research which is to gain understanding, and not to partake in moral judgment, or try to implement immediate reform (Hammersley and Atkinson, 1995).

The decision to assign pseudonyms rather than referring to participants by numbers or codes was made because I thought that it was important to talk about participants as human beings. In field notes, participants were referred to by the initial of their first name for speed and to increase the anonymity of the notes. When data was transcribed, initials were omitted and replaced with pseudonyms, and this helped me to distance myself from the data, and from any biases I might have had about particular individuals. This was important because, as Spradley (1980) has suggested, when it comes to analysis sufficient distance must be achieved to make sense of the observations. However, I did not want to distance myself from seeing the participants as people.

#### **4.4 Field relations and researcher's role**

A need to formulate well delineated protocols about a researcher's role has been expressed by a number of qualitative researchers who have worked in the field of nursing (Field and Morse, 1996; Bonner and Tolhurst, 2002; Wilkes and Beale, 2005). In ethnographic research;

*'the observer seeks to become some kind of member of the observed group. This involves not only a physical presence and a sharing of life experiences, but also entry into their social and 'symbolic' world through learning their social conventions and habits, their use of language and non-verbal communication, and so on. The observer also has to establish some role within the group'* (Robson, 2002, p314).

In order to formulate a protocol for my role, professional duties, as laid out in the Nursing Code of Conduct (NMC, 2004) and the Research Ethics Guidance for Nurses (RCN, 2004), were taken into consideration. The nature of my role was also determined by the ontological and epistemological assumptions that have underpinned this study, and have been discussed in the previous chapter. In addition, the ethical requirement to respond appropriately, if I had concerns about what I observed, influenced my role as nurse researcher. This will be discussed further in chapter 5, section 5.8.

An agreement was made with the home managers about the nature of my role, and this included that I would be supernumerary to normal staffing level requirements, that I could help out with domestic duties, such as cleaning and cooking, but that I would not carry out intimate and personal care. This was communicated to the staff at the homes, and the service users as far as possible, so that everyone had clear and shared expectations.

The importance of spending time in the field getting to know people with intellectual disabilities, prior to data collection has been well documented (Stalker, 1998). This was particularly important in this research due to the intimate nature of the research, and the need to establish whether service users were happy with my presence as part of an on-going assessment of best interests.

A second reason for spending time getting to know participants was to reduce the effect of my presence on behaviour change. People are thought to change their behaviour when being watched, and this is a problem inherent in overt observation methods, which is known as 'reactivity', or the 'Hawthorne effect'<sup>1</sup> (LoBiondo-Wood and Haber, 1998). One way to reduce this effect is to allow

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<sup>1</sup> The 'Hawthorne effect' is discussed at greater length in section 10.2.1 in relation to the validity of the findings of this study.

people to become accustomed to the researcher and acclimatised to the data collection process (Field and Morse, 1996; Robson, 2002). Therefore, Field and Morse (1996) have suggested that the researcher should be involved in all activities they plan to observe prior to actual data collection. However, due to the private nature of intimate care, I felt that it was more important for service users, as well as staff, to get to know me before I began observations of these activities. During my first visits I therefore spent time in the living room and kitchen and participated in less private activities such as meal times and watching television.

Gaining the co-operation and acceptance of service users and staff was crucial to this study and Field and Morse (1996) have written about the importance of fitting in with the norms of the group being studied. Lofland and Lofland (1984) have suggested that the selection of appropriate clothing can contribute to acceptance and to being perceived as non-threatening (Lofland and Lofland, 1984). This journal entry demonstrates that I was consciously trying to be accepted and to fit in with the staff;

*7 February 2006*

*I was careful about what clothing I wore when visiting the research settings. At meetings with managers I tended to dress more smartly, but when in the role of participant observer, I tended to dress more casually, in jeans, t-shirts and trainers, just as the support worker did.*

Whilst conducting initial visits to the homes I also made sure that I helped out wherever possible so that staff would see the benefit of having me around and that I would not get in their way. I also believed that it was ethically important for staff and service users to benefit from the research, as part of ensuring that they were not exploited, as this journal entry illustrates;

29 November 2005

*I think that my research should be mutually advantageous. Service users and staff can benefit if I help out with household chores and supporting service users with activities.*

I was reminded in supervision that wanting to be helpful and to be seen as part of the team could be a sign of 'going native'. In ethnography, the researcher must guard against 'going native', which means identifying with participants so closely that the ability to analyse from a detached perspective is lost (Hammersley and Atkinson, 1995; Silverman, 2001). The risk of 'going native' was also increased in the first research setting because Fir Tree House was a familiar setting to me. To guard against this it was therefore important to have time to step back from the setting, reflect on my involvement and discuss these issues in supervision.

Adopting the role of learner and being non-threatening to '*beliefs, self-confidence and social arrangements*' have also been recognised as important ways of getting along in the field (Lofland and Lofland, 1984, p38). This means taking the role of a novice who is ignorant about the cultural setting and who needs to be taught. However, I was aware that it was unlikely for permission to have been granted if gatekeepers had concerns about my ability to integrate and communicate effectively and respectfully with staff and service users. Furthermore, in order to gain acceptance, I needed to be able to participate in the daily activities in the home without being a burden on staff by constantly asking questions or needing constant supervision. Whilst negotiating access, and throughout my time as a participant observer, it was therefore important, at times, to demonstrate my competence, and this involved highlighting my experience and professional nursing qualification.

With specific regard to issues related to intimate care, I tried to take the role of a novice as much as possible. At times, this could be challenging as the following excerpt from my methodological journal shows;

10 November 2005

*I have a lot of experience of working in intellectual disability services and feel passionate about the way that service users are treated. In my role as a community nurse I am accustomed to visiting residential homes to offer support and give information and advice. I found that I had to be very careful, not to be seen to offer information or appear to be an 'expert'. I avoided getting actively engaged with conversations which involved staff talking about the quality of other staff's work.*

I visited Fir Tree house on five occasions with the sole purpose of giving service users and staff the opportunity to get to know me and to get used to me being around. Rapp (2000, p20) has found that '*if you hang out long enough the majority of people come to accept you*'. Having already worked at Fir Tree House meant that I had a 'head start' in gaining acceptance and it took less time for me to feel confident that I had gained acceptance than it did at Primrose Cottage, where I was initially a stranger to the staff and the service users. This explains the discrepancy between visiting Fir Tree House seven times over a three month period and visiting Primrose Cottage twenty-one times over a seven month period, before embarking on observation.

## **4.5 Time sampling**

Traditional ethnography has involved the researcher living with the social group that they are interested in studying. It was not possible to live at Fir Tree House and Primrose Cottage and was therefore necessary to negotiate appropriate time periods during which to carry out data collection. It was important to be mindful of the pressure that my presence could have put on the service, the disruption that unwelcome visits could have caused, as well as the ethical implications of engaging intimately in people's lives, and then after a period of time withdrawing.

This research also had to be conducted as part of a wider programme of study, and alongside my other work, family and social commitments.

Direct observations of intimate care were carried out between 7.00am and 9.00am, and 6.30pm and 9.00pm, as this was when service users usually had their baths or showers. Intimate care activities also took place throughout the day, for example when someone needed to use the toilet or when they required support after having been incontinent, and I therefore carried out observations at all times of the day. Both home managers advised me that it was not necessary to observe during the night because the requirement for intimate care at this time was minimal.

The homes were extremely flexible by allowing me to plan my hours of research just one week in advance. This turned out to be advantageous because initially I did not know how much time I would need to spend collecting data in relation to how much time I would need in the office transcribing and analysing the data.

I conducted data collection at Fir Tree House, nineteen times over a period of five months and this involved spending approximately fifty hours in the role of participant observer. At Primrose Cottage, data collection was carried out on seven occasions which spanned two and a half months and involved approximately twenty-four hours in the role of participant observer. Fewer hours were spent at Primrose Cottage because this was the second setting and the research became more focused as the study progressed.

I arrived for my morning visits at the start of the morning shift. In both homes, the staff met at the beginning of the shift to plan the activities for that day. During this time, staff decided who I would be able to observe having intimate care on that day. Sometimes staff tried to plan the shift to enable me to observe as many service users as possible, and I therefore constantly reinforced the message that my presence should not disrupt ordinary routines, and that they should carry on

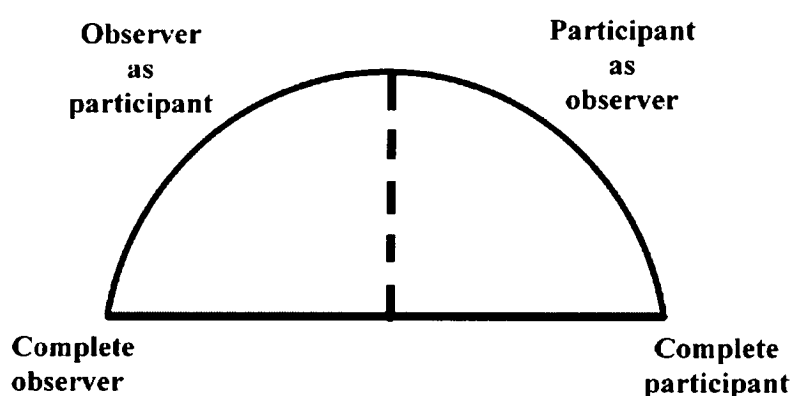


as if I was not there. I observed up to three service users having intimate care on each day, but less if two people were having their bath or shower at the same time.

## 4.6 Observer role

Junker (1960) has produced a typology of the fieldwork roles that researchers can occupy when conducting observations in qualitative research which is shown in figure 4.2.

**Figure 4.2 Theoretical social roles for fieldwork (based on Junker, 1960)**



This typology has been presented as a continuum which illustrates that the researcher's role can change depending on the extent to which they are observing or participating at any one time. Roper and Shapira (2000) have suggested that the nurse ethnographer's role is usually located somewhere around mid-point between 'complete observer' and 'complete participant', and at different times can shift along the continuum as it becomes necessary to become more involved as a participant, or more detached as an observer. My role could be located around the 'participant as observer' point of the continuum, at times moving further towards the 'complete observer' end, and at other times closer to the 'complete participant' end. To describe the approach that I used, I have

distinguished between two different roles that I adopted during this research, one whilst participating in every day activities in the home, and another whilst conducting observations of intimate care.

Whilst participating in every day activities in the home, my role was as 'participant as observer'. At these times my focus was on being a participant and gaining acceptance, with observation and data collection being a secondary concern.

Whereas, during direct observations of intimate care (which were carried out either in the bathroom or bedroom), my role was closer to the 'complete observer' end of Junker's (1960) continuum. During intimate care, I generally did not participate in activities, but stood out of the way to observe. This was unless a service user or staff member initiated interaction, if my help was needed, or if I was concerned about something that I saw, in which case I followed a protocol which is discussed in section 5.8 in the next chapter. A decision to take on the role of 'complete observer' was made following consideration of what was thought to be in the best interests of participants. This involved thinking about how each service user might respond to my presence and how I could be least intrusive. Staff advised me of where I should stand and what I should or should not do, to minimise the chance that I would get in the way or cause any distress. For example, one staff member thought that I should maintain some physical distance from Barry because he did not like people being very close to him.

## **4.7 Field notes**

It is possible to differentiate between two different types of field notes that were kept; one whilst adopting the role of 'participant as observer' and another whilst carrying out direct observations of intimate care. Whilst in the role of 'participant as observer' it was not possible to walk around with paper and pen to make extensive field notes, and I therefore had to jot down notes in a small notebook

that fitted into my pocket, or on a scrap of paper. I tried to make notes when staff and service users were not around and this sometimes meant that I had to wait until I was in the privacy of the toilet, or until I had got in my car to go home. Even though participants were fully informed of the reason for me being there, it would have been destructive to rapport to take notes in their company.

My role as 'observer' during direct observations of intimate care afforded me the opportunity to take notes whilst observing. Staff were asked to consider whether they or the service users would mind if I took notes. At Fir Tree House, no concerns were expressed. However, at Primrose Cottage, staff expressed concern that my notes might be critical or judgmental of their practice. I suggested that staff could have access to reading my notes and reassured them that my purpose was not to cast judgment but to seek understanding. Although Morse and Field (1996) have suggested that it is unwise to share initial field notes and findings with participants because this might result in increased self-consciousness and behaviour change, this advice was disregarded because maintaining ethical standards needed to take precedence over methodological considerations. In the event, only one member of staff took up the offer of reading the notes and she was happy with what had been written.

Decisions about what to record in field notes were made in accordance with theoretical sampling, a sampling strategy which is described in section 6.4 of chapter 6. Spradley (1979) has described ethnography as a research cycle with the collection of data becoming progressively narrower in scope as analysis gives direction to which areas to examine.

Spradley's (1979) advice was initially to record thorough descriptive observations by writing down everything that was observed, even if it appeared to be trivial. This was constructive in making the 'familiar strange' because events which I had not thought to be very important at the time, were subsequently found through data analysis to be relevant and important.

However, a limitation of this approach was that I might have missed seeing things because I was busy making notes. Another possible limitation was that this approach did not take account of things that did not happen and so potentially omissions would not have been available for analysis. For example, my field notes would not have included data that referred to any failings of staff to carry out certain activities, such as wash a service user's genitals, or pull back the foreskin whilst washing the penis. For this reason, I consciously tried to record things that I noticed did not happen, whilst being aware that this data was heavily influenced by my personal biases, knowledge and expectations of what I thought I should see. Consequently, this data was assigned a separate code in data analysis.

As data collection and analysis progressed, and decisions about what to record became more theoretically driven. I therefore ceased making notes about everything that I saw and heard in relation to intimate care, and instead focused on what was relevant to the specific areas that I was interested in. This meant that it was essential to pull back from the field to carry out analysis, which could then shape the focus of further observations.

Field notes were written at speed in rough handwriting and contained numerous abbreviations, and it was therefore important to transcribe the notes as soon as possible, whilst my memory of events was still fresh. As soon as possible, after each period of field work, I returned to the office to type up the notes and used this as an opportunity to write memos. Silverman (2001) has recommended that the use of symbols can make transcriptions clearer and preserve the validity of the data, and a list of those used in this study can be found in figure 4.3.

Separating my personal and subjective ideas about the data by writing them in memos, rather than in the transcribed notes, also helped to preserve the validity of the data. Memo writing was integral to analysis and will be discussed in detail in chapter 6, section 6.7.

**Figure 4.3: Key to transcriptions**

- Text that is in brackets ( ) is a description
- Text that is in square brackets [ ] is my interpretation
- Three full stops ... shows where there is missing text
- 'Single quotation marks' indicate a quote that might have been paraphrased
- "Double quotation marks" indicate an exact verbatim quote
- Present participles are used to describe action that is ongoing e.g. Barry is frowning
- The present tense is used when the start and end of an action is observed e.g. Barry frowns

**4.8 Participant accounts**

In addition to information gained through observations, Hammersley and Atkinson (1995) have argued that accounts given by the people being studied can be used for what they tell us about the phenomena being studied, and for what they tell us about those who produced them. These accounts therefore provide data that can be analysed within the theoretical framework of symbolic interactionism that has underpinned this study. Accounts that can be obtained in ethnographic research can be either 'unsolicited' or 'solicited'.

Unsolicited accounts are produced spontaneously without direct questioning from the researcher. During participant observation I found that participants sometimes made comments to me directly, often to provide an explanation about what was happening at the time. These accounts were recorded in my field notes and when analysed, they were assigned a specific code called 'staff comments' to identify them as being unsolicited accounts. Hammersley and Atkinson (1995) have argued that in field research, participants sometimes give explanations because they want to make sure that the researcher understands the situation 'correctly'. Participants might also be concerned with remedying a perceived discrepancy between their values and the actual course of events.

Unsolicited accounts can therefore provide valuable information about what the participant wants the researcher to know which could reflect their own perceptions about what they think is important.

Due to the epistemology underpinning ethnography, ethnographers have regarded unsolicited accounts as more valid data than solicited accounts because they are less influenced by the researcher than the responses participants produce from direct questioning. However, solicited accounts have the advantage of enabling the researcher to direct data collection towards areas of particular interest, and to collect information that it would be difficult to obtain in any other way. It was necessary to obtain solicited accounts in this research because intimate care was rarely talked about in everyday conversation. This is a finding which substantiates a conclusion made by Cambridge and Carnaby (2000a) that intimate care is an area of practice which is not openly discussed in residential services for people with intellectual disabilities.

At times it was possible to ask staff questions that were pertinent to the research question as part of ordinary conversation. This is a method of data collection that Spradley (1979) has called the 'ethnographic interview'. Ethnographic interviews share many of the features of a friendly conversation, and enable the researcher to minimise their influence on the participant's response and get as close as possible to an unsolicited account (Spradley, 1979). It was advantageous to ask questions in this way in order to clarify and validate interpretations I made of what I was observing. Ethnographic interviews also improved the reliability of the participant's account when conducted at the time of the event in question because they were not affected by lapses in memory, which can be a problem for accounts that are given retrospectively. However, I did have to wait for an appropriate time to write down what had been said, and the accuracy of ethnographic interviews was therefore dependent on my own memory.

The extent to which I was able to conduct ethnographic interviews was limited because I needed to find appropriate opportunities to ask questions, and also because my questions needed to be relevant to the conversation, and not to appear from 'out of the blue'. It was therefore necessary to obtain solicited accounts by conducting formal, pre-planned interviews, and this type of interview has the advantage of allowing the researcher time to decide what questions to ask and how to phrase them (Robson, 2002).

Hammersley and Atkinson (1995) have argued that regardless as to whether accounts are solicited or unsolicited, they are subject to researcher effects, and also that conducting interviews in an artificial environment is a source of potential bias. However, both types of account can be valuable if researcher effects and artificiality are taken into consideration when interpreting the data. The implications of the potential for accounts to be biased as a result of researcher effects will be examined further in chapter 10, section 10.2.1.

#### **4.8.1 Formal interviews**

Decisions about when to conduct interviews, who to conduct them with, and what questions to ask were based on theoretical sampling, and this involved selecting participants and data pertinent to the categories that had been identified in earlier stages of analysis.

Even though participants had given consent for me to carry out participant observation, they retained the right to decline being interviewed. Being observed and being interviewed placed different requirements on participants, and it was therefore good practice to ask for consent separately. Prior to giving consent, staff were given an 'Information Sheet for Interviews' (see appendix 8), a verbal explanation of the interview process, and asked to sign a Consent Form for Interviews (see appendix 10). In total, six formal interviews were carried out at Fir Tree House. It was not necessary to conduct formal interviews at Primrose

Cottage because sufficient data had been collected through observation, unsolicited accounts and ethnographic interviews. This was achieved because my skills of obtaining data through ethnographic interviewing had improved as a consequence of the experience and practice I had gained at the first research setting.

The times for interview to be held were agreed with the manager and staff. Afternoons were generally chosen because this was the quietest time of the day when staff were least likely to be engaged in other duties. Interviews were restricted to a maximum of thirty minutes in order to minimise disruption and were only carried out at times when service users were either out of the house or did not need the direct support of staff to continue their usual activities. The manager allowed the use of the office for interviews. This seemed to be the most appropriate location because it was where service users seldom spent their time and where the interview could take place in privacy.

Before interviews started, I checked that the interviewee had read the information sheet and signed the consent form and that they were still happy to go ahead. I made it clear that participants could end the interview at any time. I also asked if I could tape record the interview and all interviewees agreed to this. At the beginning I explained that the purpose of the interview was to find out about experiences of intimate care and that there were no 'right' or 'wrong' answers. I encouraged participants to think of it as an ordinary chat and to forget that the tape recorder was on. Participants did appear to be at ease whilst the tape recorder was on, but the accounts they gave are likely to have been influenced by the unavoidable formality of the interview setting, and the impact of this on the validity of the findings is discussed in chapter 10, section 10.2.1.



### 4.8.2 Interview schedules

In ethnographic research, it has been suggested that interviews should be non-directive and unstructured (Spradley, 1980). However, as Hammersley and Atkinson (1995) have pointed out, in order to direct the interview to elicit responses pertinent to the research, an interview must have some structure. The style of interview used in this research can best be described as semi-structured, because the semi-structured interview;

*'Has predetermined questions, but the order can be modified based upon the interviewer's perception of what seems most appropriate. Question wording can be changed and explanations given; particular questions which seem inappropriate with a particular interviewee can be omitted, or additional ones included'* (Robson, 2002, p270).

Lofland and Lofland (1984) have described a procedure for developing a 'topic guide' for semi-structured interviews. This procedure begins with writing down a list of 'puzzlements', which are the researcher's ideas about areas that they want to explore further. The puzzlements that I wrote down included areas that needed clarification and questions I had about the thoughts, feelings and beliefs of staff participants that it was not possible to access through observation. The list of puzzlements was too long for all to be pursued through interview and therefore needed to be reduced by focusing on those which related to the theoretical direction that the research was taking. The selected puzzlements were then sorted into categories and used to formulate interview questions.

A number of texts have provided advice on how to word interview questions in qualitative research. Robson (2002) has suggested that questions should not be ambiguous or cause confusion, and that double-barrelled, leading or biased questions should be avoided. Closed questions should also be avoided and

replaced with open-ended questions, which Robson (2002) has suggested can facilitate the participant to speak openly and freely and allows the researcher;

*'to make a truer assessment of what the respondent really believes'*

(Robson, 2002, p276).

Spradley (1979) has identified over thirty different types of interview question which fall into three broad categories. These categories are; descriptive, structural and contrast. Examples of questions used in this research that fall into these categories are;

- Could you tell me what you do when you arrive at work in the morning?  
(descriptive)
- What are all the different activities involved in intimate care? (structural)
- What are the different ways that intimate care is carried out? (contrast)

Spradley (1979) has suggested that interviews should begin with descriptive questions, which are non-threatening and easy to answer because these type of questions help to put the interviewee at ease. Structural questions also served the purpose of obtaining descriptive accounts of intimate care in the staff's 'native' language. The importance of native language is that it enables the researcher to represent the meaning that is encoded in language more closely (Spradley, 1979). As the interview progressed, I moved on to ask structural and contrast questions. The questions that were asked were also constructed within a symbolic interactionist framework and therefore focussed on questions about;

- Process (e.g. what do you do when you are giving a bath?)
- How (e.g. how did you learn what to do?)
- Experiences (what were your first experiences of providing intimate care like?)

The interview schedules can be found in appendix 16. In keeping with the semi-structured approach that was taken, these schedules were not followed rigidly. This was because the researcher's main technique when interviewing is to listen intently and allow the respondent to tell their story with minimal disruption (Field and Morse, 1996). Participants were given as long as they needed to answer questions. Prompts, probes and further questions were only provided when the respondent's answer had 'dried up' or when they digressed to talking about topics that were of no relevance to intimate care. My responses were minimal and consisted of nodding, smiling, looking interested and making encouraging sounds of acknowledgement or agreement such as 'mhh'.

In order to promote rapport and encourage the participant to feel comfortable, I attempted to mirror my body language and communication to the respondent's. When transcribing the tape recordings of the interviews it was evident that I had adapted my communication style and language according to language used by the participant. If a participant was quietly spoken, my voice was quieter, and if the participant used colloquial language, I did too. These are established techniques for developing rapport in interview settings (Johnson, 2001).

When the interview was drawing to an end, I prepared the participant for closure by saying something like '*we are nearly out of time and this will be the last question*'. I learnt to do this after I ended my first interview somewhat abruptly which surprised the participant who said '*oh, is that it?*' I also asked participants if they wanted to say anything else before the tape recorder was switched off.

Participants were given positive feedback to minimise the risk of them going away and feeling anxious about their 'performance'. Some participants asked '*was that ok?*' in a manner that suggested that they wanted to please me and that they were concerned about their performance. I provided this reassurance by saying '*that was really interesting*', or '*that was really good*'. I also thanked the

respondent and asked if I could interview them again at another time if I had more questions.

Immediately after the interview, I made notes to record any initial ideas I had about the participant's answers and behaviour. Transcription usually took place the day after the interview and never longer than three days after. This was important so that the interview was still fairly fresh in my mind and I could remember details about the interview that could not be captured in the tape recording. During one interview, the first side of the tape finished, and when I turned it over, I did not press the record button properly which meant that a part of the interview was not recorded. I realised immediately after the interview and made notes to record as much as I could remember about what had been said. This part of the transcription was marked to identify that it was not a verbatim account.

## **4.9 Documents**

In ethnographic research, documents are often used as supplementary forms of data. A list of documents that were collected and included in data analysis can be found in appendix 17 and consisted of; policies, procedures, care plans, risk assessment and support guidelines. These documents existed before the research commenced and their construction was therefore not influenced by the research in any way. Charmaz (2006) has referred to this type of document as 'extant texts'.

In addition, the notes that had been taken during meetings with the home managers, staff meetings and telephone conversations were transcribed in full and included in analysis. In keeping with the interpretive approach that has been taken to this research, it was recognised that these were socially constructed by participants and the researcher (Jupp and Norris, 1993).

Documents were therefore subjected to analysis within the same interpretive approach that was used for observation and interview data.

#### **4.10 Preparing the data**

These data consisted of seventy transcriptions, documents and texts, consisting of a total of 80,288 words. This vast amount of data needed to be stored and organised in a safe and logical way so that it could be easily located and retrieved. The data was therefore saved as word documents with a standard format used to give each document a descriptive title, and to record the date, the research location and participants who were present. The precise times and duration of each period of data collection was also recorded. Extant texts were re-typed with the participant's name omitted so that the data could be saved as a word document and included in analysis.

#### **4.11 Ending data collection**

After reading Guba and Lincoln (1981), my understanding was that data collection should end when there was a sense of regularity and repetition in the data, and when a small amount of additional information was being produced in relation to the amount of effort required. The following excerpt from my methodological journal shows when I felt that this point had been reached;

*21 September 2006*

*I am observing the same patterns over and over even though this is only the fifth time I have carried out direct observations at Primrose Cottage. Is this because I am missing seeing anything new or because there is nothing new and of importance to observe? Am I always looking for the same thing and therefore always finding the same thing?*

The answer to the question that I posed in the above excerpt came from gaining a deeper understanding of 'theoretical saturation'. According to Marcus (1995), no matter how many cases are studied, it will never be possible to observe everything that could ever happen in a setting. Therefore data collection should be theoretically driven (Strauss and Corbin, 1998), and theoretical saturation;

*'refers to the point at which gathering more data about a theoretical category reveals no new properties nor yields any further theoretical insights about the emerging grounded theory'* (Charmaz, 2006, p189).

I could have continued to carry out observations *ad finitum*, and undoubtedly I could have made new observations and gained new insights that would have taken me in different theoretical directions. However, the direction that this research took was towards the construction of a grounded theory within the theoretical framework of symbolic interactionism. Researchers must guard against 'synomorphism', which involves collecting data beyond what is needed to answer the research question (Guba and Lincoln, 1981). Data collection therefore ended when theoretical saturation had been achieved, and there was nothing new that was being added to the emerging grounded theory. After conducting this research in two homes data collected was of sufficient breadth and depth that theoretical saturation was achieved. This is why, although the initial intention was to access three homes, it was decided that the inclusion of two homes in this research was sufficient and that further data collection would be unnecessary.

## **4.12 Summary and conclusion**

Before moving on to the next chapter, this one closes by summarising and making some overall comments regarding the methods used in this study. A combination of methods, which were adopted from the research tradition of ethnography have been used to illuminate the experience of intimate care. The

precise way in which the methods were used unfolded throughout the course of the study using theoretical sampling, and this means that the data collected was relevant to the research question and faithful to what was found in the research settings. Data collection and analysis were carried out concurrently and this enabled the study to be shaped and focused using both deductive and inductive processes, and also for the resulting development of theory to be inextricably linked to the data. Before describing the process of analysis in chapter 6, the next chapter examines the ethical issues that have been raised in this chapter.

## Chapter 5: Applied ethics and consent

*'Countering the need for beneficence, however, is the equally strong need to ensure that individuals with intellectual disabilities are not unfairly excluded from research that could benefit either the subjects themselves or the population of individuals with ID as a whole' (Lai et al, 2006, p115).*

### 5.0 Introduction

Ethics is the philosophical study of values, morals and morality and covers the analysis of ideas about what is 'right' and 'wrong'. It is imperative that research is carried out within sound ethical principles and this involves obtaining informed consent from participants (DoH, 2005). Informed consent presents particular challenges when involving people with intellectual disabilities in research, and these issues become even more challenging when involving people who have severe and profound intellectual disabilities. The ethical debates surrounding the inclusion of people who lack capacity to consent are complex and place an obligation on researchers to articulate and justify rigorous ethical procedures. In this present research, Beauchamp and Childress' (1989) 'four principles approach' has been used as a framework to consider potentially competing ethical perspectives. The methods that have been used to include people with severe and profound intellectual disabilities ethically form an integral part of this research and the articulation of these methods in this chapter, and elsewhere (for example Clark, 2007), make an original contribution to knowledge.

This chapter commences with a discussion of the importance of ethics in all research involving human participants, and then more specifically for research involving people with intellectual disabilities. The chapter then considers the requirement for informed consent and the implications this has for research with people with severe and profound intellectual disabilities. This is followed by a description of the methods that were used to obtain consent, firstly for



participants who lacked capacity to consent, and secondly for staff who were able to give informed consent. When conducting this research it may have been necessary to respond to poor, abusive or dangerous practice, and the final part of this chapter describes the approaches that were used to address this issue in a way that would protect the rights and well-being of all participants.

## **5.1 The importance of applied ethics in research**

Ethics has long been a subject of philosophical debate but its application to research has only been a matter of serious consideration towards the end of the twentieth century. Paternalistic attitudes to research have tended to prevail, and have afforded researchers with the authority to make decisions about what should be researched and who should be researched on (Oliver, 1992; Zarb, 1992). This culture has allowed researchers to make decisions based on a belief that research leads to the advancement of knowledge and is therefore 'for the greater good'. Section 3.6 in chapter 3 has shown that, at times this has been at the cost of the rights, well-being and autonomy of people with intellectual disabilities (MacInnes, 1999).

Since the development of the human rights movement in the 1960's, there has been an incremental pressure on researchers to demonstrate that their research does not harm the individuals involved. However, certain groups of society have remained particularly vulnerable to the exploitation of researchers, and over recent history serious violations of rights have been committed in the name of research. The sterilisation, euthanasia and medical experimentation programmes that were carried out by the Nazi's during the Second World War were among the most serious examples of unethical research that has been reported (MacInnes, 1999). These atrocities were made public during the Nuremburg Trials, and as a result the Nuremburg Code of Ethical Practice 1949 made it necessary for human subjects to give their voluntary consent. However, history has shown that the code failed to have an adequate impact on protecting

vulnerable people because abusive research has continued to be carried out without the consent of those involved (Hershey and Miller, 1976).

The ability of people with severe and profound intellectual disabilities to protect their rights is extremely compromised due to their limited communication abilities, lack of autonomy and the reliance they have on others to meet essential needs in their daily lives. This group is therefore one of the most vulnerable and easiest to abuse in the name of research. A more recent example of abusive research was the 'Willowbrook experiment' which involved children with intellectual disabilities being injected with hepatitis so that researchers could observe the effects of the disease (Beecher, 1966). Such examples of unethical research have been brought to public attention and this has prompted political debate resulting in the publication of a number of policies and professional codes of conduct to govern the way that research is carried out. The Research Governance Framework for Health and Social Care has stated that;

*'the dignity, rights, safety and well-being of participants must be the primary consideration in any research study' and that 'informed consent is at the heart of ethical research' (DoH, 2005, p7).*

In order to protect vulnerable people from exploitation, the government has therefore placed an obligation on researchers to obtain participants informed consent, and this has specific implications for people with intellectual disabilities.

## **5.2 Informed consent**

In relation to research, 'informed consent' means making a 'reasoned judgment' about participation which must be based on having sufficient information about the research in order to make that judgment (RCN, 1998). In law, a person must have 'capacity to consent' to be able to give valid informed consent (DoH, 2001b).

In order for consent to be valid a person must be;

- 1) capable of taking a particular decision (competent)
- 2) acting voluntarily (free from undue pressure or duress)
- 3) provided with enough information to make the decision (DoH, 2001b).

To be competent to make a decision a person must be able to comprehend and retain information material to the decision and use and weigh this information in the decision making process. Individuals are presumed to have capacity unless there is reason to believe otherwise, and furthermore an assessment of an individual's capacity to consent is only valid for the decision that it has been assessed for (DoH, 2001b).

By virtue of the cognitive and communication difficulties of the people with severe and profound intellectual disabilities who participated in this study, the government's criteria for capacity to consent to this research were not met. In order to have had capacity to consent, participants would have needed to understand what the research would involve and be able to communicate their decision to participate. Although attempts were made to explain the purpose of my involvement to participants, there was no indication that participants had been able to understand the information.

When this research was carried out, the law in relation to carrying out research with people who are unable to give consent was unclear (DoH, 2001b). After the study commenced, the Mental Capacity Act 2005 received royal assent and came into full effect in October 2007 (Mental Capacity Implementation Programme, 2007). This Act has recognised the injustice of people who lack capacity to consent being excluded from research, and also the necessity to ensure that if these people are to be included, their rights and well-being must be protected. For example, excluding people with severe and profound intellectual

disabilities from research can also be abusive if it excludes them from new forms of intervention that might assist them. The Act has therefore clarified the legal requirements of involving people who lack capacity in research. When this present research commenced, the Act had not come into force, but the approaches that were used did meet the expectations set out by this new legal framework.

The decision to include people with severe and profound intellectual disabilities in this research was therefore based on the guidance that was available at the time, and this included Royal College of Nursing and Department of Health publications (RCN, 1998; RCN, 2004, DoH, 2001b; DoH, 2005). The Royal College of Nursing (RCN) has suggested that research should only be carried out with people who lack capacity to consent if it cannot be carried out with adults who do have capacity (RCN, 1998). This research could not be carried out with participants who did have capacity, because as chapter 2, section 2.8, has argued, there are problems with applying research findings from other groups to understand the unique experiences of people with severe and profound intellectual disabilities.

The RCN (2004), have acknowledged that sometimes there is no viable alternative to including people who do not have capacity to consent, but have noted that undertaking research ethically with vulnerable groups is more difficult. This difficulty has meant that vulnerable and minority groups have often been 'invisible' in research and this places extra demands on researchers to ensure the appropriate involvement and protection of vulnerable groups (RCN, 2004). The use of an ethical framework has been used to consider the ethical merits for and against including people with severe and profound intellectual disabilities who lack capacity to consent in this present study.

### **5.3 Ethical framework: Beauchamp and Childress' four principles approach**

Ensuring the dignity, rights, safety and well-being of research participants is a complex issue and a number of competing arguments can be made to support various courses of action that a researcher could take. Beauchamp and Childress (1989) have proposed that the four basic ethical principles are autonomy, justice, beneficence and non-maleficence and that these can be used as a framework to guide decision-making. Beneficence refers to doing good for others, and involves weighing up benefits and risks. Non-maleficence is the principle of doing no harm, and justice is about 'fairness', which in nursing includes decisions about the allocation of resources. Autonomy refers to the ability of an individual to determine their own course of action and it is this principle, along with the principle of non-maleficence that underpins the need for informed consent.

Nurse researchers must strive to meet ethical standards that are associated with all of these principles; however, the implications of each principle can be in conflict, which may leave a researcher with a dilemma of having to choose which should be prioritised above others (RCN, 1998). For example, in relation to this research, the principle of justice suggests that people with severe and profound intellectual disabilities should have the opportunity to benefit from participation in research, but the principle of autonomy might suggest that individuals who lack capacity to consent should not be involved. The framework can therefore not be used as a straight forward formula, but it is useful for helping to focus the researcher's mind on the ethical dilemmas that need to be considered when undertaking research with human participants.

The argument for this research being in participants' best interests rests on a belief that research can make a valuable contribution to people's lives; and this idea is related to the ethical principle of beneficence. However, Homan (1991)

has argued that carrying out research with people who are unable to consent is symptomatic of paternalistic attitudes which have been considered to do harm because they lead to a failure to acknowledge individual autonomy. However, I would argue that the lack of understanding we have, about the needs and experiences of people with severe and profound intellectual disabilities, has meant there is a risk of everyday care and support being provided in a paternalistic way because according to Carnaby and Cambridge (2006b) carers use their own judgments, opinions and experiences to determine how to provide that care. Through systematic research it may be possible to overcome some of the paternalism that exists in service provision and to develop a greater understanding of needs and wishes from the service users' perspective.

Kellett and Nind (2001) have pointed out that there is often a tendency to talk about the power of research to do harm, but there is also a potential for research to do good. This refers to the ethical principle of beneficence. The review of the literature presented in chapter 2, has found that there has been very little research about the lives of people with severe and profound intellectual disabilities (see section 2.2). This might suggest that the need for informed consent, which is underpinned by the principles of autonomy and non-maleficence, has taken precedence over the argument that it is unjust to deny people from the benefits of research, which is an argument underpinned by the principle of justice.

The ethical implications of carrying out research with people who are unable to consent must therefore be considered alongside the ethical implications of excluding them from research all together. Lai *et al* (2006) have suggested that;

*'the ethics of research with vulnerable populations is characterized by a conflict between the principles of benevolence (which can be interpreted in these cases as a need to protect the vulnerable) and justice (the need to*

*see that the benefits of research are equally distributed throughout the population)*' (Lai *et al*, 2006, p115).

In order to weigh up the implications of the various courses of action, decisions should therefore be made by assessing what is in a participant's 'best interests'. The RCN (2004) have suggested that, when making decisions about best interests, researchers should begin by answering two questions; 'how important is the research question that is posed?' and 'can the proposed research answer the question?'

By way of answer to the first question, this thesis has argued that the need for research into intimate care in the lives of people with severe and profound intellectual disabilities is long overdue. The reasons for this have already been discussed in section 1.4 of chapter 1, where it was argued that, research is particularly needed in the area of intimate care because;

- There has been very little research carried out in this area (Cambridge and Carnaby, 2002), and in order to develop good practice there needs to be an understanding about how people experience intimate care.
- People with severe and profound intellectual disabilities rely on others to support them with very intimate activities on a daily basis.
- Intimate care occupies a large amount of time and the quality of care is likely to be a factor which contributes towards determining quality of life (Currie *et al*, 1999).
- Intimate care is carried out in private where it cannot be easily monitored.
- There is a significant risk of abuse associated with intimate care (Cambridge and Carnaby, 2000a).

In relation to the second question 'can the proposed research answer the question', chapter 3 has discussed the potential of this research to extend our understanding of how people with severe and profound intellectual disabilities

experience intimate care. This potential is based on there being methodological coherence between the research question, methodology and the epistemological and ontological assumptions underlying the research approach. It could therefore be concluded that conducting this research was in the best interests of the population of people with severe and profound intellectual disabilities as a whole. However, this does not establish whether the research was in the best interests of the individuals who would be directly involved as participants.

So far this chapter has argued that there exists both the sufficient and necessary evidence to support the inclusion of people who lack the capacity to consent in this research, providing that there are grounds for believing that the research is in each individual participant's best interests. Determining best interests involved further exploration of the risks and benefits of participation in relation to each potential participant.

## **5.4 Best interests**

According to the Department of Health (2001b), researchers must be able to justify a decision to involve people who lack consent on the basis that it is the person's best interests. For the purposes of this research, this involved weighing up the risks and benefits of participation in the research in comparison to the risks and benefits of not participating. The National Bioethics Advisory Committee (1998) has suggested that participation in research can bring both direct and indirect benefits. The direct benefits of this research could have included potential for improved quality of care, and the indirect benefits might have included;

*'diversion from routine, the opportunity to meet with other people and to feel useful and helpful, or greater access provided to professional care and support'* (National Bioethics Advisory Committee, 1998, p11).



The benefit of developing a relationship with a researcher was particularly relevant for people with severe and profound intellectual disabilities whose social lives may be impoverished and who are less likely to access professional care and support (Emerson *et al*, 2005). It was also possible to contribute to the lives of people being studied by providing access to academic and professional information that I was privy to from working in a University and in a Community Team for People with Learning Disabilities. The idea that participants can benefit from the researcher contributing in some way to their lives has been referred to as a 'trade off' (Lofland and Lofland, 1984). The benefits that I could offer the homes, for example by helping out with chores were described section 4.4 in the previous chapter. The managers of both homes also thought the research would be beneficial because it would prompt discussion and provide opportunities for staff to engage in reflection on practice. In addition, I offered to provide the staff team with feedback at the end of the research and to facilitate staff discussions related to my research findings. Arguably, some participants may have gained an intrinsic reward from contributing to the advancement of knowledge that had the potential to benefit other people whose lives are affected by intimate care.

Having considered the potential benefits of participation, consideration needed to be given to the ethical principle of non-maleficence, and the potential risks that this research presented. It was difficult to quantify the risks involved in this study because the method used was non-invasive and presented no obvious or significant risk to physical safety. However, the method of observation did involve a violation of privacy, and this meant that there was a risk of causing participants to feel uncomfortable, embarrassed or distressed.

Subsequent to the commencement of this research, guidelines provided by the International Association for the Scientific Study of Intellectual Disabilities (IASSID) recommended that;

*'any risk should not exceed those that are attached to the provision of routine support or therapy, medical or psychological treatments'* Dalton and McVilly, 2006, p63).

When considering the principle of non-maleficence, my main concern was to ensure that my observations did not add any further violation of privacy and did not cause any distress or harm, and this was an issue that I often discussed during supervision.

Little is known about how lack of privacy affects people with severe and profound intellectual disabilities, but in section 2.8 of chapter 2 it was acknowledged that even if people are accustomed to receiving intimate care we cannot assume that they do not experience embarrassment or distress. However, it could be argued that the researcher's presence would present no additional embarrassment or distress than was the norm. This is because the people who were asked to participate in this study were used to different people being involved with the provision of their intimate care, with more than one person being present during intimate care, and with new members of staff watching whilst undergoing their induction. Although this research did involve an infringement of privacy, one of the reasons for carrying out this research was, paradoxically to try to gain an insight into how this was experienced. The idea that people with severe and profound intellectual disabilities need to give consent in order for a researcher to observe them during intimate care arguably suggests that they should also give their consent for staff to provide intimate care, but in reality this rarely happens, as illustrated in the following excerpt from my journal;

*24 May 2005*

*Research is a curious thing. When I contacted one home, the manager agreed to have a student on placement and suggested that she could be involved with intimate care, but also thought that I would not be able to*

*carry out my research because the service users would not be able to give consent. Why should there be a difference?*

The sensitive and private nature of this research meant that it was of paramount importance to carry out rigorous assessments to determine best interests by weighing up the relevance of the risks and benefits that have been discussed in this section for each individual participant. In order to obtain a valid assessment of best interests, two methods were used. The first method involved asking others to provide 'consent by proxy', and the second involved assessing indications of 'implied assent'. The way that consent by proxy and implied assent have been used in this study combine to make an original approach that has enabled the researcher to balance the implications of the ethical principles of autonomy and non-maleficence with those of justice and beneficence. These methods will now be described in detail.

## **5.5 Consent by proxy**

Consent by proxy means giving consent on someone else's behalf. An important difference between involving children in research and adults is that, whereas parents or guardians can provide consent for their child;

*'no-one (not even the person's parents, or others close to them) can give consent on behalf of adults who are not capable of giving consent for themselves' (DoH, 2001b, p10).*

It has been argued that to ask parents to give consent for an adult to participate in research would be to;

*'collude with in the idea that people with learning difficulties are eternal children' (Stalker, 1998, p9).*

In the research carried out by Stalker (1998), the approach taken was to obtain consent from a professional on an adult's behalf. However, there have been criticisms against the idea that professionals are best placed to make decisions on behalf of people with severe and profound intellectual disabilities and a call for the involvement of parents and family in making choices (PMLD Network, 2002). The Mental Capacity Act 2005 has recognised that consultation with parents and family is an important and necessary part of deciding whether adults who lack capacity should be involved in research, and this view is endorsed by IASSID (Dalton and McVilly, 2006). The ethical validity of including parents and family in decision making rests on an assumption that people who lack capacity would want their carers to make decisions on their behalf. This belief is supported by Bach and Rock's (1996) 'decision making model', which recognises that people typically make decisions by consulting with people who are close to them and with who they trust.

The ethical validity of consent by proxy also relies on the ability of proxies to make decisions that are in the individual's best interests. Iacono and Murray (2003) have reviewed the sparse amount of research that has attempted to determine the basis upon which proxies make decisions about consent to research or medical treatment. They have suggested that proxies do make decisions based on what they think is in the person's best interests, and also on what they think the individual's preferences or wishes might be. Involving more than one person in providing consent by proxy has also been thought to provide a more valid judgement of the person's best interests (Iacono and Murray, 2003).

It was therefore important to identify the most appropriate people to give consent by proxy. The intention was to identify advocates, members of staff and relatives of potential participants, because these people were thought to have concern for their best interests and to be most likely to know the person well. This was similar to the 'circles of support' approach, which has been used to help people who have limited communication abilities benefit from Person Centred Planning

(O'Brien and O'Brien, 1996). A circle of support is made up of people who know and care for an individual and who are thought to be in the best position to advocate and make decisions on that person's behalf.

However, a problem with this approach is that many people with intellectual disabilities have few people in their lives other than paid staff; many do not have much contact with family, and relatively few have an independent advocate (Emerson *et al*, 2005; Llewellyn, 2005). In this present research; none of the participants had an advocate and neither of the participants at Fir Tree House had a family who were available or willing to be consulted. IASSID have suggested that when family members cannot be consulted, collective professional decision making can be more effective in safeguarding participant's best interests (Dalton and McVilly, 2006).

In this research, the circle therefore comprised the home manager, the person's key worker and four other members of staff. At Primrose Cottage, some of the service users did have parents who could provide consent by proxy. The home manager of Primrose Cottage also identified the care manager and community nurse as appropriate people to contribute to providing consent by proxy for participants. Everyone who was asked to provide consent by proxy was given a copy of an 'Information Sheet for Friends, Relatives and Carers' (see appendix 6) and provided the opportunity to meet with me to discuss the research and ask questions. However, the parents were happy with the information they had been provided and did not think that it was necessary to meet with me. All of the people who were asked to give consent by proxy agreed that participation would be in the service user's best interests.

Before seeking consent by proxy, the home managers had identified service users who they did not want to participate in the study. Some service users did not meet the inclusion criteria for this research because they could attend to their intimate care needs semi-independently. Others had challenging behaviour, and

it was thought that being observed during intimate care might have made the behaviour worse. However, there were other service users who staff thought might actually enjoy having the extra attention of a second person's presence during intimate care and it was for these people who proxies were consulted.

The staff, manager and professionals who provided consent by proxy were found to be very cautious when making a decision, and this could have suggested that they did not make the decision lightly, as illustrated by this extract from some notes that were taken after a meeting with a care manager;

*22 August 2006*

*'The care manager asked lots of questions and was clearly interested in what I was doing and interested in making a sound judgement about whether it was in each of the service users best interests to participate. She appeared to focus on whether or not each person would be able to communicate whether or not they were happy with me observing them during intimate care.'*

Decisions by proxies were backed by logical explanations and rationale, and this was evident from the way they discriminated between service users who they thought would not want to be involved, and those who might. Proxies were keen to ensure that the research would benefit participants by providing services with information that could lead to better quality and more individualised care.

This method of obtaining consent by proxy was not without limitations, and one of these was that 'best interests' is a complex and subjective concept that cannot be assessed objectively. In this research, the process of obtaining consent by proxy was co-ordinated by myself, and it is possible that my own views influenced the decisions given by members of the circle of support. My objectivity was compromised because I had an interest in wanting people to participate and I could therefore have been biased towards encouraging the

circle to give consent. The Research Governance Framework (DoH, 2005), has stated that researcher should aim to empower participants, but because I co-ordinated obtaining consent by proxy, it was largely unavoidable that I would retain a degree of power and control.

Ideally, if resources had permitted someone who was independent from the research would have co-ordinated the processes involved in obtaining consent by proxy. As this was not possible, strategies were employed to reduce the influence of my opinion on the proxies' decision as much as possible. This included providing detailed information about the research and making it clear that proxies should err on the side of caution. This involved advising proxies that if they had any inkling that participation might not be in the person's best interests, they should make this clear. In addition, every proxy had to agree that participation was in the individual's best interests for them to be included.

Strategies were also employed which are thought to make a researcher's actions open to scrutiny, and these included keeping an audit trail and discussing issues with academic and professional colleagues for opinion and feedback (Silverman, 2001). Opportunities for such feedback arose from presenting a paper on Ethics and consent to a group of multi-disciplinary intellectual disability professionals, and at an international research conference (Clark, 2007).

To summarise, a service user was only included in the study if everyone was in agreement that it was in their best interests, and so for example, if just one person had doubts about an individual, that individual would not have participated. The limitations involved in using consent by proxy meant that it was important to check that the 'right' decision had been made, and therefore rigorous methods of assessing 'implied assent' were also put in place.

## 5.6 Implied consent and implied assent

Capacity to consent is a legal construct based on an individual's ability to meet the criteria identified earlier in this chapter. Dye *et al* (2004) have argued that this construction has led to a 'single dichotomous categorisation', whereby an individual is assessed as either having, or not having capacity to consent to a particular decision. According to Dye *et al* (2004), this does not serve to empower people with intellectual disabilities because inevitably someone else makes decisions on their behalf. It is therefore incompatible with models of research practice that combine participant research with empowerment and self-advocacy.

Dye *et al* (2004) have proposed that it would be more helpful to present the concept of capacity to consent within a broader contextual framework which includes the concept of risk-benefit assessment in which the seriousness of consequences determines the level of capacity needed. Therefore even if participants have been assessed as lacking capacity to consent to research, they may be able to effectively demonstrate capacity if their behaviour is assessed over time. In a similar vein, Knox *et al* (2000) have suggested that consent should be seen as an on-going process.

In a clinical context, the term implied consent is used when a person's behaviour is taken as a sign or expression of their compliance. An example of this could be when a person holds out their arm to have an injection. Applying this to a research context, Sachs *et al* (1994) used the term 'assent' which referred to, the willingness of the subject to go along with, or not object to, a proposed study. The term assent more accurately applies to this study because participant's behaviour was regarded as an indication of their willingness to go along with what was happening and was not taken to mean that they were giving their consent to participate in the research. By assessing implied assent, the intention was to try to empower participants by allowing them to have as much control as



possible over their participation. This is clearly not a fail safe method because to be truly empowered individuals would have needed to have capacity to make the decision, but assessing implied assent was thought to be an important step towards promoting autonomy.

The use of implied assent has been endorsed by The Mental Capacity Act 2005, which has made it clear that even if a person lacks capacity to consent they must not be excluded from the decision making process. The method is also consistent with IASSID's recommendation that when participants are unable to give fully informed consent a mechanism of '*process consent*' should be formalised (Dalton and McVilly, 2006, p62). The procedure for assessing implied assent was therefore carried out, not as a one off event, but as an on-going process that continued throughout the course of this research. This involved assessing the individual's non-verbal communication and their responses to the research and the researcher. It is important to acknowledge that there is a difference between assenting to being observed and to allowing the data collected from those observations to be used in the context of a research study. This is one of the reasons why obtaining implied assent was not sufficient to allow a person to participate, and why it was also necessary to obtain consent by proxy.

The first stage of assessing implied assent was to make an assessment of whether I had developed rapport with each participant. This assessment began before observations of intimate care commenced and was based on the interactions I had with participants during my initial visits to the home that were described in section 4.4 of the previous chapter. The assessment was made by the staff team who had seen how the participant had reacted to the research.

Assessing implied assent relied on having a good understanding of the meanings of participant's facial expressions, behaviours and vocalisations. The validity of implied assent rests on an assumption that it is possible to interpret facial

expressions, vocalisations and behaviours as meaningful communication (Porter *et al*, 2001). Some research has suggested that it is possible to make valid inferences based on the non-verbal communication of people with severe and profound intellectual disabilities, and also that carers are intuitively skilled at identifying distress cues (Hogg, 1998; Aylott, 2001; Regnard *et al* 2007). However, the use of implied assent is problematic if observers do not make the correct inferences, and in a study by Grove *et al* (1999), it was found that observers sometimes made invalid inferences. Hogg *et al* (2001) have also found that observers showed significant variation in judging communication of affect. These findings highlight how subjective assessments of implied assent are, and that caution should be taken when interpreting the meaning of non-verbal behaviours.

The idea of using communication profiles as a tool to help assess implied assent came from having experience of using 'communication passports'.

Communication passports contain user friendly information that enables people to understand and interpret non-verbal communication (Millar, 1997). At Fir Tree House, participants already had communication passports, which could be used to underpin an assessment of implied assent. However, at Primrose Cottage, this information was not available and therefore time was devoted to developing 'communication profiles' upon which an assessment of implied assent could be based (see appendix 13). To do this, information about participant's communication was compiled from staff, people who had provided consent by proxy and speech and language therapists' assessments.

It was found that participants had clear ways of communicating when they were not happy and that staff believed that they were able to interpret non-verbal communication well, as the following excerpts from meetings and discussions with staff and professionals illustrate;

*I asked staff how we would know if Barry was not happy with my presence. Sharon said that he would shout 'Arggh' (loudly) and "karate chop". This was demonstrated by Sharon and described as 'like doing a star jump'. Jane agreed.<sup>1</sup>*

*Sharon said that 'When unhappy Simon bites his fingers and scrunches up his face and nose' (Sharon demonstrated this). 'He picks things up and throws them'. "He makes it obvious when he does not like something, you will know".*

*The community nurse told me that although Wendy would not be able to indicate consent she would be able to indicate dissent. She could do this by withdrawing physically in her chair, lashing out, pushing and screaming. The community nurse said that she would 'play up' if she did not like a person who was giving her personal care.*

The communication profiles and communication passports therefore included details of the behaviours that service users demonstrated when they were thought to be unhappy or distressed and were used as a guide to help to interpret participants' responses throughout the research. If participants had showed signs of being distressed or unhappy as a result of being observed during intimate care, then the research would clearly not have been in their best interests and they would have been withdrawn.

The process of assessing implied assent continued throughout the entire period of participant observation. I made sure that every time I wanted to observe an individual carrying out intimate care, I checked with the member of staff that it was acceptable, both for themselves, and for the service user who I would be observing. During staff meetings, feedback was requested on views about how

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<sup>1</sup> Verbatim quotations are in "double quotation marks" [" "], and non-verbatim quotations are in 'single quotation marks' [' '].

participants were responding to my presence and to being observed during intimate care. However, all of the participants were thought to respond positively to the research, and no reason was given to suggest that their participation should cease.

It is recognised that the methods and procedures described in this chapter were not a perfect solution to gaining valid consent from people who lack capacity, and it is hoped that as our understanding of this group develops, the approaches that are available will be improved. For example, the development of instruments for measuring emotion and mood of people with severe and profound intellectual disabilities, such as the Interact Short Form (Liu *et al*, 2007), may help future researchers to make more valid assessments of implied assent. However, this chapter has shown that, this present research has used approaches that were based on the ideas of best practice that were available at the time. A summary of the approaches used is provided in figure 5.1.

**Figure 5.1: Summary of methods used to gain consent**

- Staff team put forward names of people whose best interests might be served by participating in the research
- A circle of support was identified
- Information sheets were distributed to members of the circle of support and opportunity was given to ask questions
- Members of the circle met with the researcher to discuss the implications of the research for the individual
- If all members agreed that it was in the person's best interests to participate an assessment was made of how they would demonstrate implied assent
- Communication passports were consulted or a communication profile was developed
- An assessment was made of how well the individual had responded to the researcher
- Implied assent was assessed throughout

## **5.7 Gaining informed consent from staff**

The ethical requirement to obtain consent also applied to the staff who participated in this study. However, the way that this was addressed was entirely different to the approaches described above, because staff had capacity to give their fully informed consent. As discussed earlier in this chapter, for capacity to consent to be lawful, researchers have an obligation to provide participants with sufficient information for them to make a reasoned judgement about whether or not to participate (DoH, 2001b). The RCN (1998) have given researchers advice on the type of information that should be provided. For the purpose of the study, this included informing staff about any potential risks, time commitments, what would happen to the research findings once the study was completed, and where further information could be obtained.

An implication of disclosing information of this nature is that it is not possible to carry out research covertly. As Hammersley and Atkinson (1995) have pointed out, there is a danger that if participants know what the purpose of the study is, they are more likely to change their behaviour, and this could reduce the validity of the findings. However, the principal consideration was for the protection of the rights and well-being of participants, and this meant a decision was made to fully inform staff participants about the nature and purpose of the research, as far as possible.

To ensure that adequate information was given a 'Participant Information Sheet' was developed and, as with all information sheets and consent forms used in this study, it was submitted to the Ethics Committee for their scrutiny. The Participant Information Sheet, which can be found in appendix 7, gave details of the purpose of the research and what participation would involve. It also clearly stated the participant's right to withdraw from the research at any time. This form was based on a pro forma that had been produced by Thames Valley University's Faculty of Health and Human Sciences Research Review Committee and on

Research Ethics Guidance for Nurses (RCN, 1998). In addition, potential participants were given a verbal explanation of the research and provided with opportunities to ask questions during staff meetings and my visits to the home.

If members of staff agreed to participate they were required to sign a written consent form (see appendix 9). Attempts were made to ensure that staff did not feel any pressure to sign the form and were encouraged to take the information away so that they had time to consider their decision. Contact details for the researcher and research supervisor were also provided so that questions could be asked at any time. All members of staff, who were asked, gave their consent. Some signed the consent form as soon as they were given it, and others signed up to three weeks later.

The willingness of staff to participate came as a surprise to me because, when planning the research, I had thought that staff might find the idea of being observed whilst carrying out intimate care to threatening or intrusive. Concern that I would be 'checking up on staff' was raised by one member of staff who asked me during a staff meeting if I would 'be critical'. I recorded the response that I gave in the following field notes;

*20 August 2006*

*No, there are no real standards for care at present. Therefore, although I might do things in a slightly different way to how you would do it, there is no way of knowing that my way is right. However, there is a procedure that I must follow in the event of witnessing dangerous or poor practice. [Described later in this chapter.] The person asking this question explained that she did not really mean 'critical' but rather that I am not there to tell staff what to do. I said 'no, you are the experts'. Staff responded with some humorous disagreement!*

It is possible that some staff might have felt ambivalence towards participating in the research. However, the impression staff gave me was that they thought the research could have a positive impact on the lives of the people they were working with, and also that intimate care was an important area of practice that had been neglected in training as the following excerpt from my field notes illustrates;

*James talked at some length about how he thought that the research I am doing is important because of the lack of training that is offered for intimate care.*

However, I was aware that some participants might have felt pressure to participate if everyone else, including their manager, was keen for the research to go ahead. This was a concern that I recorded in these field notes;

*3 February 2006*

*I have met with the manager of Primrose Cottage today. The meeting went well and the manager is keen for the research to go ahead. The manager is going to speak to the rest of the staff team. This raises issues around the rest of the staff team feeling that they can make their own decisions about participation.*

I tried to address this problem by reminding staff that they had the right not to participate and that they could decide to withdraw from the study at any time, without needing to give a reason. I also asked for consent for interviews separately, and as explained in section 4.8.1 of the previous chapter, staff were required to sign a separate consent form for this. No staff withdrew from the study and none gave any indication that they were not happy to participate. However, after interviewing one participant, I did learn from a home manager that she had felt uncomfortable, and I had also noticed that she seemed quite anxious. Although she told me that she was willing to be interviewed again, I did

not ask her because I felt that this would have been ethically inappropriate knowing that it was likely to cause her anxiety.

This chapter has argued that informed consent requires a researcher to be open and honest about the purposes of the research and what it will involve. However, Lofland and Lofland (1984) have pointed out that all research is 'secret' to some degree because participants are not told absolutely everything about the research. Furthermore, in ethnographic research, the exact course of the research cannot, nor should be pre-determined. This meant that it was particularly important for participants to be aware of their right to withdraw from the research at any time and to maintain an open dialogue throughout the course of the research in order to discuss any changes and developments as they arose.

Keeping participants updated about the day to day running of the research, such as how long it would take and how often I needed to visit, was fairly straight forward. However, it was more difficult to determine how much I should tell participants about the content of my research findings, as these journal entries illustrate;

*17 July 2006*

*I feel uncomfortable carrying out a literature search for 'dehumanisation' because I feel that it is unfair to the people who I have been studying, and that some of the potentially negative findings I am making are about aspects of practice that are common place in intellectual disability services. It would not have been appropriate to discuss this with participants because it could have been taken as criticism and resulted in a hostile response. However, I also thought that when reading about dehumanisation, I might find that the way I have worked with people with intellectual disabilities in the past could have contributed to, or been a result of dehumanising processes. And this suggests that I have not*



*judged the individuals I have observed or taken the moral high ground. As Barton (1976) has said, it is important not to criticise individuals, but only to criticise their actions.*

*11 August 2006*

*I found myself being quite vague and simply telling staff that it was 'going very well.*

The issue of what to tell participants was raised in a supervision session and it was agreed that the most appropriate course of action would be to report the findings of the research at the end of the study when analysis had been properly thought through and feedback could be given in a reasoned way.

Another ethical dilemma arose because, prior to consent being given, my visits to the homes gave me access to data that was potentially relevant to this research. From an ethical perspective, knowing what to do with this data was not a straight forward issue, as this journal entry shows;

*3 August 2006*

*During the period of getting to know staff and service users, staff have talked to me about their experiences of intimate care and I have made observations and overheard conversations related to this aspect of care. It seems appropriate and necessary to make notes that are related to methodology and to keep an audit trail, but should I record what people say and what I observe about intimate care? Whether or not I record these observations, it was not possible for me to completely disregard them, because they have started to form my understanding of what I am observing and will therefore affect the way that I think about the phenomena I am studying. It is possible that I could decide to only include data in the thesis that I have obtained after consent has been given. I*

*found it frustrating when I have made relevant and potentially valuable observations and not been able to record these in detail.*

The data included in the findings chapters refers only to data collected subsequent to consent being given. However, the issue was not of such great concern because all participants had given their consent. What would have been a concern was if some staff had decided not to consent to take part in the study, but had been present at times when I was collecting data.

This section has described the methods that were used to gain informed consent from staff, and some of the ethical dilemmas that were encountered related to this issue. This chapter now turns its attention to the ethical issues of dealing with the potential for observing practice that was poor, dangerous or abusive.

## **5.8 Dealing with poor, dangerous and abusive practice**

This research undoubtedly allowed me privileged access to witnessing areas of practice that usually remain unseen. The literature has suggested that abuse is more likely to occur in places where it is less likely to be seen, and this could therefore be during intimate and personal care because these activities are usually carried out behind closed doors (Cambridge and Carnaby, 2000b; Joyce, 2003). It was therefore important to consider what actions I should take if I observed or suspected poor, dangerous or abusive practice, with due regard for my responsibilities, both as a researcher and as a registered nurse.

Research and nursing are distinct professional roles, and have distinct aims, bodies of theoretical literature, and professional codes of conduct. At times these roles can conflict, and Bonner and Tolhurst (2002) have suggested that nurse researchers need to find a balance between the two. As a researcher, the aim of my role as 'participant as observer' was to observe intimate care whilst influencing the actions of the people I was observing as little as possible.

However, in the event of witnessing abusive or dangerous practice, I had a duty as a nurse, as well as a moral obligation, to take action. This duty took precedence over maintaining the role of participant observer. The Nursing and Midwifery Council's Code of Professional Conduct has instructed nurses that;

*'When facing professional dilemmas, your first consideration in all activities must be the interests and safety of clients'* (NMC, 2004, p9).

However, determining whether to take action in the event of witnessing 'poor practice' was problematic, because ideas about what constitutes 'good practice' and 'poor practice' are subjective, and are culturally and socially defined. It was therefore important to construct a protocol of the actions I should take in the event of witnessing practice which I deemed to be poor, and to differentiate this from dangerous and abusive practice. A protocol was drawn up following discussions with the home managers and my supervisor, and a flowchart was constructed which gave clear indications for the response I should take in the event of having concerns about practice (see appendices 14 and 15). The Care Homes Regulations; National Minimum Standards (DoH, 2003b), the local Vulnerable Adults Policy and the Social Care Workers Code of Practice (General Social Care Council, 2002) were referred to in order to determine what should constitute acceptable and unacceptable standards of practice. Consideration was also given to the NMC Code of Professional Conduct, which has stated that a registered nurse has a duty to;

*'act quickly to protect patients and clients from risk' and 'where you cannot remedy circumstances in the environment of care that could jeopardise standards of practice, you must report them to a senior person with sufficient authority to manage them'* (NMC, 2004, p9).

The flowchart that was developed required a distinction to be made between situations requiring immediate action, and those that did not place the individual

in immediate danger, but could be construed as poor practice. Throughout the course of the research, I did not observe practice that put anyone at immediate risk. However, I did observe practice that concerned me and the remainder of this chapter presents some examples of these situations.

This incident occurred during one of my early visits. At approximately 4.30pm I was in the living room with three service users, a female member of staff and a male member of staff. Another female member of staff was preparing dinner in the kitchen. One lady was hoisted from her wheelchair onto the toilet before dinner every day. A risk assessment stated that two members of staff were required to use the hoist to reduce the risk of accidents. On this particular day, the female staff asked the male staff to help her. This concerned me because the home manager had told me that intimate care for females should be carried out by female staff, and also because my personal view was that females should always be supported by female staff (unless they requested support from a male). I decided to take immediate action by asking the support worker if it was acceptable for a male staff to assist this lady in the bathroom. I was told that it was acceptable providing no female members of staff were available. I did not think that I could question this further without checking the home's policy and speaking to the manager.

When I later asked the manager, he told me that the home did have a policy on 'Cross Gender Personal Care' which had been written by the County's Social Services Department in 1994. The policy stated that service users had a right to choose either 'same gender' or 'cross gender' care and that choice should be respected where possible. The policy also stated that 'safety and competency' should be the over-riding factor in personal care, and acknowledged that there would be times when it would not be possible to offer preferred gender care. I asked the manager, for his interpretation of this policy and he told me that as far as possible, female staff should always provide personal care for female service users, but at times when female staff were not available it was acceptable for

male staff to assist. I told the manager about the incident and he thought that the male staff should have been asked to cook dinner, so that the two female staff were available to carry out intimate care.

On another occasion, I was carrying out an observation whilst an agency staff member was supporting a gentleman to get ready for bed. The member of staff was preparing to give the gentleman a shower, but I was concerned because I knew that he did not usually have a shower in the evening and that disrupting his routine might cause him distress. I decided to intervene by asking the staff if the gentleman usually had a shower in the morning and the evening. Asking this question appeared to make him realise his mistake. Raising the point by asking a question was a way of intervening without being critical or confrontational and enabled me to treat the staff participants as the 'experts' whilst I maintained the role of being a 'learner'.

There were other times when I observed aspects of practice that were not consistent with my own standards. Some of these practices appeared to be the 'normal' way of doing things in the particular home, or with a particular service user. If I had made a comment that was interpreted as being critical it could have been damaging to rapport, and at times it was therefore appropriate for me to 'bite my tongue'. This is illustrated by an entry to my journal, which I wrote after visiting one of the homes and observing a member of staff refusing to allow one gentleman a drink;

*21 June 2006*

*I feel so strongly that David should be able to have a drink and I wanted to ask staff why he was not allowed to but was worried that my question would have sounded confrontational and threatened the rapport that I had developed. I decided not to say anything at the time but to check to see if there were any written guidelines first.*

The use of supervision was invaluable for discussing such issues and concerns and ensuring that my actions would be in the best interests of the participants. It was important for all those involved in the research to be aware that I would discuss issues with my supervisor in the context of assuring confidentiality, and this point was made explicit in the 'Information Sheet for Participants' (see appendix 7). Supervision enabled me to make a more rational and objective judgment about what action to take, and prevented me from jeopardising the research by being challenging or over-critical. After such a discussion on one occasion, it was thought that the most appropriate course of action would be to raise these issues at the end of the research, whilst feeding back the results of the study. This also enabled me to protect the anonymity of the individual staff who I had observed.

With regard to dealing with poor practice and protecting the well-being of participants, it was also important for staff to be able to report any concerns they might have had about the research, or about my conduct. Normal procedure was for staff to follow the whistle blowing policy, and this would have involved reporting concerns to the manager. However, I had a good relationship with the managers of both the homes, and staff might not therefore have felt confident to talk to the managers if they had concerns about my conduct. In accordance with guidance from the Royal College of Nursing (RCN, 1998), it was therefore important to identify someone else, from outside of the immediate staff team who staff could speak to if necessary. The line manager of Fir Tree House and the care manager for the service users at Primrose Cottage were both in regular contact with the respective homes and agreed to take on this role. To my knowledge, in the event, no concerns were raised.

## 5.9 Summary and conclusion

To summarise and conclude this chapter, people with severe and profound intellectual disabilities are a vulnerable group who are at risk of being exploited by researchers. However, this group also have a right to be included in research, if that research has the potential to bring benefits to their lives. In order to protect the rights and well-being of the people who participated in this study, a number of safeguards were put in place. It was important that my work was fully supervised, open to scrutiny and that I was open to constructive criticism from peers. Within the guidance provided by the Research Governance Framework (DoH, 2005) and the Mental Capacity Act 2005, which has subsequently come into force, the methods and procedures described in this chapter have ensured that high ethical standards have been maintained throughout fieldwork and data collection. The next chapter gives an account of the approaches that were used to analyse these data.

## Chapter 6: Analysis

*'Just as painters need both techniques and vision to bring their novel images to life on canvas, analysts need techniques to help them see beyond the ordinary and to arrive at new understandings of social life'* (Strauss and Corbin, 1998, p8).

### 6.0 Introduction

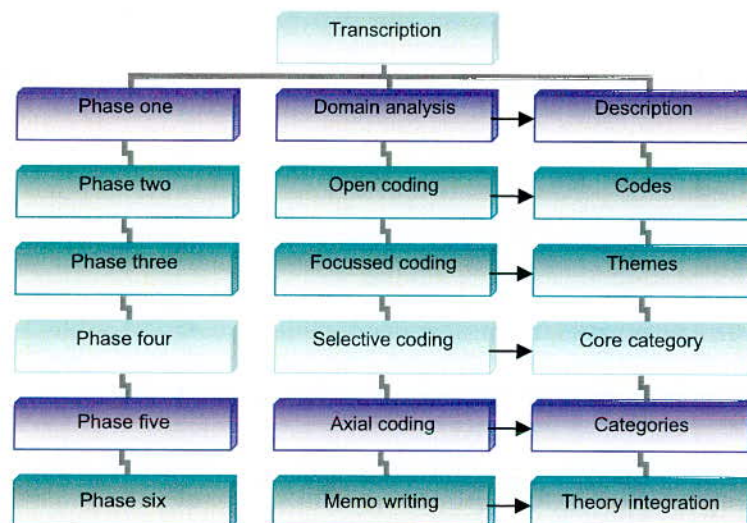
This chapter describes the approaches that were used to analyse the data collected in this study. Qualitative analysis involves interpreting data in order to discover patterns and themes, which can be organised into a theoretical explanatory scheme (Strauss and Corbin, 1998). However, there is no single accepted set of conventions for qualitative data analysis, and numerous labels have been used to describe various approaches that have been taken (Robson, 2002). The data analysis tools used in this study were taken from grounded theory, as well as those more commonly associated with ethnography, and were selected because of their appropriateness to the data, and their coherence with the philosophy of this study. Grounded theory uses the method of constant comparison, which combines explicit coding procedures with analytic theory development to generate categories, properties and hypotheses in order to develop an integrated theory about a phenomenon (Glaser and Strauss, 1967). The tools and techniques used for data analysis in this study were informed by, and adopted from, the work of Glaser and Strauss (1967), Spradley (1979; 1980), Lofland and Lofland (1984), Hammersley and Atkinson (1995), Strauss and Corbin (1998) and Charmaz (2006).

Data analysis in this study consisted of six phases. These phases are illustrated in figure 6.1. Constant comparative analysis is a recursive process, which involves coding simultaneously at different levels (McCann and Clark, 2003; Charmaz, 2006). Analysis therefore did not proceed in a linear step-by-step



fashion. However, in order to make this research transparent and open to scrutiny, this chapter describes the process of data analysis as six sequential phases. This means that the flowchart depicted in figure 6.1 does not provide a completely accurate representation of reality, but is useful for providing a schematic overview of the processes involved in analysis. The flowchart shows that prior to phase one, analysis began with the transcription of field notes, interview tape recordings and documents. The six phases are then listed in column one. The second column shows the process involved at each phase, and the third column shows the outcome of each phase, which culminated in theory integration.

**Figure 6.1 Phases of analysis**



## 6.1 A note on qualitative data analysis software: MAX qda

As previously said, qualitative analysis is a complex process and a vast amount of these data were collected in this study (totalling 80,000 words). This made the use of computer software invaluable to assist with data analysis. Both Hammersley and Atkinson (1995) and Robson (2002) have discussed the advantages and disadvantages of using computer software packages for the analysis of qualitative data. On balance, the use of qualitative data analysis software was advantageous to this study because it allowed for experimentation, revision and refinement of coding schemes, and made the location and retrieval of data easy (Hammersley and Atkinson, 1995).

The software used in this research was MAX qda<sup>1</sup>, and was chosen because it has sophisticated coding and retrieval functions, a clear layout, and is straightforward to use. MAX qda enables the researcher to code data thematically, and to use categories to organise the codes hierarchically using sub-codes. The software allowed for retrieval of all data that had been assigned to a code, and also for easy location of the data within the transcript or document that it originated from. MAX qda provides colour and symbol coding which aided the retrieval process and helped to visualise the emerging coding system. The colour coding function was also used to identify data that related to my involvement or interaction with the participants and this was valuable for maintaining reflexivity. However, conceptually, the process of analysis is the same as when analysis is conducted manually and, as Hammersley and Atkinson (1995, p198 and p203) have pointed out, software does not replace the need for the researcher to *'exercise his or her intellectual imagination'* and *'there is no mechanistic substitute for those complex processes of reading and interpretation'*.

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<sup>1</sup> MAX qda is a qualitative data analysis software programme that has been named after one of its designers.

At the outset of data analysis, a decision had not been made about which software package to use, and the first phase of analysis which is described in the following section, was therefore conducted manually, using paper, pencil and highlighters.

## **6.2 Phase one: descriptive analysis**

The first phase of analysis involved developing a description of intimate care. This involved identifying and classifying elements of intimate care, and the social and environmental settings in which it took place and using 'native' language to convey what was going on, what the setting looked like and what the people in the setting were doing. This research set out with an open research question, and exploratory aims, and at phase one of analysis, it had not yet been established that data would lead to the development of grounded theory. It was only after analysing these data using ethnographic methods to produce a description of intimate care that the possibility of developing theory became apparent. The tools used for descriptive analysis were taken from Spradley's (1979) 'Developmental Research Sequence' (DRS).

As part of the DRS, Spradley (1979) has designed a 'descriptive matrix', which in this present research, was used to deconstruct the activities involved in intimate care and the elements of the environment in which it took place. The matrix contains eighty-one boxes, but for the purposes of this research it would have been futile to produce such a highly detailed description, and therefore only the key boxes, which focussed on; 'space', 'object', 'act', 'activity', 'event', 'time', 'actor', 'goal', and 'feeling' were completed. The completed matrix can be found in appendix 19, and a narrative description of intimate care can be found in appendix 20.

Spradley (1979) has suggested that a description of a cultural setting can be used as the basis for the discovery of 'cultural domains', which are categories of cultural meaning. According to Spradley (1979);

*'Every culture creates thousands of categories by taking unique things and classifying them together'* (Spradley, 1979, p88).

The discovery of cultural domains enables the researcher to describe a social situation and the cultural patterns within it. An integral feature of this approach is that it is inductive and domains are not pre-imposed on the data, but are discovered directly from the data.

Domains, as cultural categories, are made up of three basic elements: a cover term, included terms, and a semantic relationship (Spradley, 1979). The cover term is the name given to a cultural domain; included terms are the names for the smaller categories within the domain; and the semantic relationship describes how they link together.

The steps that are taken in domain analysis are identified in figure 6.2.

#### **Figure 6.2: Steps in domain analysis**

- Step one: Select a single semantic relationship (*e.g. what are all the kinds of?*)
- Step two: Prepare a domain analysis worksheet (see appendix 18)
- Step three: Select a sample of field notes
- Step four: Search for possible cover terms and included terms that fit the semantic relationship (*e.g. what are all the kinds of activity?*)
- Step five: Repeat the search for domains using a different semantic relationship (*e.g. what are all the ways to?*)
- Step six: Make a list of identified domains

(From Spradley, 1979, p93-97, *italics added*)

The discovery of domains can be used as 'sensitising concepts' in the manner described in section 3.5 of chapter 3 (Blumer, 1954). These domainssensitised me in knowing what to look for when I returned to the field to conduct more data. I therefore continued to search for more included terms, as well as for new cultural domains. When new domains were identified, it was necessary to go back to data that had already been analysed to search for included terms that 'fitted' the new domain.

At first it was quite difficult to identify domains, but once I had got to grips with the approach, the value of using semantic relationships to search for cultural domains became apparent, as the following excerpt from my methodological journal illustrates;

*2 January 2006*

*It took a while to work out how to search for domains. However, once started, many themes and domains were identified from just a few pages of observation notes.*

Figure 6.3 lists the fifty-three cultural domains and the eleven semantic relationships that were used to identify the domains and their included terms.

Figure 6.3: Summary of domain analysis worksheets

Semantic Relationship <i>Form</i>	Cover term for cultural domains
<b>Strict inclusion</b> <i>x is a kind of</i>	Act; Activity; Place; Object; Choice offered; Object of reference; Person; Relationship; Time; Feeling; Goal; Facial expression; Non-verbal response; Facial expression; Non-verbal response
<b>Means – end</b> <i>x is a way to</i>	Cooperate; Be uncooperative; Prepare; Cover up; Wash; Communicate the need to go to the toilet; Obtain sensory experience; Communicate emotion; Make you do something; Demonstrate preference; Control the environment; Cope with intimacy; Refer to private parts of the body; Interact (service users); Interact (staff); Offer choice; Control; Demonstrate care; Experience intimate care
<b>Cause – effect</b> <i>x is a result of</i>	Rushing; Wanting everything to run smoothly; A lack of concern for privacy; Intimate care being a shared activity
<b>Cause-effect</b> <i>x results in</i>	Humanising; An apology
<b>Cause-effect</b> <i>x leads to</i>	De-humanisation
<b>Rationale</b> <i>x is a reason for</i>	Carrying out intimate care (in a particular way); Giving an explanation; Rushing
<b>Function</b> <i>x is used to / x is a function of</i>	Let you know what is happening; Clean or wash / Intimate care
<b>Function</b> <i>x is terminology used to</i>	Refer to intimate and personal care; Talk to / call service users
<b>Attribution/characteristic</b> <i>x is an attribution of / x has</i>	A support worker / Has sexual undertones
<b>Spatial</b> <i>x is a place for</i>	Intimate care
<b>Sequence</b> <i>x is a step in</i>	Intimate and personal care

Although it is accepted that all descriptions are selective, domain analysis forced me to look at all of the data in a very thorough way, and therefore reduced the extent to which the description was influenced by making subjective choices based on what struck me as being particularly important.

Spradley (1979) has suggested that the discovery of cultural domains is a prerequisite for theoretical analysis. As previously explained, following preliminary analysis of these data, a decision was made to conduct theoretical analysis using tools of analysis from grounded theory, and this takes us to phase two of analysis, which involved searching for themes in the data using the method of constant comparison.

### **6.3 Phase two: open coding**

Open coding involved taking each sentence and identifying which group or class of phenomena it belonged to, and then grouping these data in accordance with a coding system. The method of constant comparison was used to code data and this involved looking for similarities and differences in these data and grouping data together into concepts (Glaser and Strauss, 1967). Strauss and Corbin (1998) have suggested that open coding can be used to discover concepts from the data by closely reading a line or sentence of data and asking questions like; 'what is going on here?', 'what is this all about?', 'what is the person saying?', and 'what do these actions and statements take for granted?'

According to Gibbs and Taylor (2005), codes can be based on themes, topics, ideas, concepts, terms, phrases and keywords, and the range of things that can be coded include; behaviours, acts, events, activities, strategies, practices, states (general conditions experienced by people), meanings, participation, relationships, interaction, conditions, constraints, consequences, settings, and reflexive feelings. Codes must be grounded in the data and arise from the data,

rather been imposed in the data *a priori* (Strauss and Corbin, 1998). It was therefore necessary to devise and experiment with codes that were relevant to the data collected throughout this study. In the constant comparative method, data is constantly revisited until it is clear that no new themes are emerging. The description of intimate care obtained in phase one of analysis provided a starting point for developing a coding system, because description can be used as a basis for more abstract interpretations and for conceptual ordering and theorising (Strauss and Corbin, 1998).

Sentence by sentence coding was used in this study, rather than line by line coding because, as far as possible, observation notes had been written in such a way that each sentence contained just one unit of meaning, or one idea (i.e. one verb, noun or adjective). The notes had been written this way purposefully in order to make the data as clear and precise as possible and also to make coding easier.

Interview texts and documents contained longer sentences, than observation transcripts, and sometimes needed to be broken down so that constituent parts, or individual words, could be analysed separately. For example, if a sentence referred to 'shaving' and 'independence' the sentence was assigned to two themes. This illustrates the complexity of these data, and also highlights a pitfall, or limitation that would have resulted if a reductionist approach had been taken that did not allow for multiple interpretations of the data to be made.

In open coding, researchers are encouraged to look for multiple meanings and to consider the range of what is plausible by making alternative interpretations of the data (McCann and Clark, 2003). This is a reflection and acknowledgement of the ontological position that sees the nature of the social world as having multi-realities. Strauss and Corbin's (1998) 'flip flop technique' was used to elicit different perspectives on the events, actions and interactions that were observed. This involved turning concepts 'upside-down', or 'inside-out' in order to examine



opposite or extreme interpretations. The technique is useful for helping the researcher to avoid taking one particular stance to the data and for opening up areas which require further clarification (Strauss and Corbin, 1998).

Although, according to Strauss and Corbin (1998), it is not necessary to subject all of the data to sentence by sentence coding, I found that doing so forced me to consider all of the data and not to be biased towards focusing on certain data I immediately had thought to be important. This was a valuable approach for finding the 'strange in the familiar' (Garfinkel, 1967), as the following extract from my methodological journal illustrates;

*1 September 2006*

*I have just been reading over the observations looking for some vignettes for a presentation that I am going to be giving on intimate care and it occurred to me how mundane the data appears to be at first glance. It is only when conducting open coding that the complexity and possible theoretical relevance of the data becomes apparent.*

The data was therefore fragmented using a number of codes which were constantly revisited and revised. An example of a coding system that was developed during analysis can be found in appendix 21. Provisional labels and definitions were assigned to the codes to ensure that the use of each code remained consistent (see appendix 22 for an example).

The codes identified during analysis covered a wide range of characteristics and patterns related to intimate care, and the scope of this range was too broad to subject all of the codes to more detailed analysis. As explained in section 4.7 of chapter 4, '*ethnographic research should have a characteristic funnel structure, being progressively focussed over its course*' (Hammersley and Atkinson, 1995, p206). Progressive focussing involves a gradual shift from describing events and social processes to developing explanations and theories. In order to

progressively focus the research, it was necessary to select the most significant codes, and to develop these into conceptual themes. This was achieved using theoretical sampling and 'focussed coding'.

## 6.4 Phase three: focussed coding

The codes or 'themes' that were selected for further analysis are shown in alphabetical order in figure 6.4. In order to explore the intimate care experiences of people with severe and profound intellectual disabilities, within the theoretical framework of symbolic interactionism, a decision was made to focus on the observable activities and interactions between service users and staff and what these could reveal about experiences of intimate care. At this stage, codes were also selected for further analysis if they related to issues that were prominent in the pre-existing literature on intimate care, or if they were thought to be important because, for example, they appeared frequently in the data collected in this study.

**Figure 6.4: Codes selected for further analysis**

- All the same
- Attributing higher ability
- Control and choice
- Coping with intimacy
- Dignity and respect
- Disinhibition
- Empathy
- Humour
- Naked
- Open doors
- Rushing and time taken
- Shaving
- Sexual Connotations
- Sorry
- Staff comments
- Waiting

(2 September 2006)

The themes listed in figure 6.4 were identified directly from the data and were therefore used as a basis for theoretical sampling. In theoretical sampling the researcher aims to develop and define theoretical categories by seeking data pertinent to the themes that emerge through analysis (Charmaz, 2006).

Theoretical sampling involves simultaneous coding and data collection, and enables the researcher to control the process of data collection based on the theory that emerges throughout data analysis (Strauss and Corbin, 1998). Data analysis and data collection therefore formed an;

*'iterative process whereby data analysis feeds into subsequent data collection with this then stimulating further analysis'* (Robson, 2002, p487).

As data collection and analysis progressed, themes were refined and similarities and differences between the themes were examined as a basis for grouping them together into higher order and more abstract conceptual categories. In grounded theory all categories are regarded as provisional and must be checked against the data and the relevant literature (Charmaz, 2006).

Deciding on a focus for this research meant disregarding potentially valuable and important analytical ideas. The aim of the research had been to find out about the *experiences* of people with severe and profound intellectual disabilities, and the data relating to communication would have been very interesting and valuable to pursue. However, this would have required more extensive work in collaboration with a Speech and Language Therapy service, and would have involved long term observations and assessments of communication in a variety of contexts and settings. To do this would have been beyond the scope of this PhD study, and would have required a separate application to the ethics committee for approval. It has therefore been acknowledged that a limitation of this research is the lack of understanding gained about the communication and non-verbal behaviours of the people with severe and profound intellectual

disabilities who participated in this study and this will be discussed in more depth in section 10.2.2 of chapter 10.

## 6.5 Phase 4: selective coding

The process of re-organising data around a core category has been referred to as 'selective coding' (Strauss and Corbin, 1998). The aim of grounded theory is *'to generate a theory to explain what is central to the data'* (Robson, 2002, p439). This involves finding a central core category which is both at a high level of abstraction, and which is grounded in the data and establishing links between this and other categories (McCann and Clark, 2003).

Strauss (1987) has listed six characteristics of a core category;

- It appears frequently in the data
- It helps to explain most of the variation in the data
- It links easily with other categories
- It has implications for formal theory
- As it emerges from the data, the theory is able to progress forward
- It permits maximum variation in the analysis

As a result of further data collection guided by theoretical sampling, 'dignity' emerged as a common property to all of the themes. Due to the relevance of dignity to these data, and the potential theoretical significance of dignity for understanding the experience of intimate care, dignity was selected as the phenomenon around which other categories could be organised to develop theory. Therefore, although initially, dignity was thought of as a property of the themes (with a dimensional range from maintaining dignity to dignity being lost), dignity will be referred to as a 'core category' because in grounded theory research, the label 'core category' has been used to describe central phenomena around which all other categories are integrated (Strauss and Corbin, 1998).

Data collected in this study suggested that dignity was linked to ideas about seeing people as fully human, and that it may have comprised of various sub-properties, as the following excerpt from an early coding scheme in figure 6.5 shows.

**Figure 6.5: Excerpt from a coding system**

- Asking questions which cannot be answered
- Seeing individuality
- Mimicking
- Politeness
- Empathy
- Attributing thinking
- Viewing other as reciprocating
- Control and choice
- All the same

(5 October 2006)

Given the significance of dignity to the emerging theory, at this point it seemed appropriate to consult the extant research and theory on this concept by conducting a review of the relevant literature. As explained in chapter 2, section 2.2, literature that *'illuminates, supports or extends the proposed theory'* can be used as a form of data and *'interwoven with the empirical data'* (Hutchinson, 1993, p205). Literature can also be used as an approach for validating theory (Strauss and Corbin, 1990). Dignity is a subjective concept, and it was therefore important to compare what I considered to be dignified or undignified with the literature, in order to develop a theory that aligned with, and contributed to an established body of knowledge. The literature revealed that there was no established, clear conceptual framework within which to understand dignity, and subsequently a model was developed using concept analysis.

Concept analysis has been described as a process used to determine similarities and differences between ideas about a concept, and to create a tentative

definition (Haddock, 1996). It is a complex process which can involve observation, reflection and immersion in the data (Fenton and Mitchell, 2002). A concept is a mental formulation of empiric experience, and by empiric it can be assumed to be shared and understood by others (Haddock, 1996).

Concept analysis involved examining the literature and the data and putting together a list of all the properties of dignity, grouping them together conceptually, and cross referencing them. Properties and ideas that were supported by more than one source were retained, and those that only appeared once were discarded. A full list of the properties and ideas, and the authors from which they derived, can be found in appendix 23. The findings from this examination of the literature were interwoven with data collected in this study to produce a model of dignity, and this process will be described in further detail in section 7.1 of chapter 7.

It is important to make it clear that the core category 'dignity' was identified following scrutiny of the emergent themes in this study. The idea that dignity would be central to the findings made in this study was not a pre-existing idea that was imposed on the data, as this excerpt from my methodological journal affirms;

*9 August 2006*

*At the beginning of the PhD, I remember talking to people who thought that dignity and respect would be central to the thesis. I did not think that these ideas would be particularly prominent in what I observed...<sup>2</sup> It is important that I did not consciously aim to look for data that would support theories about dignity because this shows that I was not consciously biased towards looking for data to prove my preconceived ideas, but rather that the theory emerged from the data.*

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<sup>2</sup> See appendix 2 for full account.

The following excerpt demonstrates the interplay between deductive and inductive thinking, which was central to the analytic processes used in this research. Ideas emerged from these data through a process of inductive analysis, and were then compared to the literature and to other data in the manner of deductive analysis;

*14 August 2006*

*I am trying to decide on a story line or thread that runs through my findings so that I have a focus point from which to develop a coherent argument. The themes that I have been focusing on have a property of dignity and some of the variation in this data appears to be accounted for by variations in the extent to which the person with severe and profound intellectual disabilities is regarded as being fully human. This relates to literature on humanisation and de-humanisation and links to some established theoretical works. However, the link between these theoretical ideas and intimate care has not been made before and so pursuing this theoretical direction provides the potential for making an original contribution to knowledge. There are a number of themes, which immediately spring to mind as being associated with this idea such as 'waiting', 'rushing' and 'routines', and I need to look to see whether there are others.*

In grounded theory research it is usual to describe selective coding after axial coding. However, as stated earlier in this chapter, data analysis is iterative, and moving through the stages of analysis was not a linear process because the identification of a core category prompted me to go back to re-analyse the data using focussed coding with the core category 'dignity' in mind. The core category was also used in axial coding to make links between categories by considering what each category is conveying and hypothesising relationships between them in relation to dignity.

## 6.6 Phase five: axial coding

Axial coding is also known as theoretical coding (McCann and Clark, 2003; Charmaz, 2006), and is used to bring data back into a coherent whole by answering questions about when, where, why, who and how and with what consequences (Strauss and Corbin, 1998). This allows the researcher to describe the studied experience more fully and to link categories at a conceptual, rather than descriptive, level (Charmaz, 2006).

In order to answer these questions, Strauss and Corbin (1998) have used a scheme or framework within which to organise categories. This scheme includes 'actions and interactions', 'conditions' (the circumstances that form the structure of the studied phenomenon), and 'consequences' (the outcomes of the actions and interactions), and therefore addresses issues of 'process'. By addressing the question of 'process', this scheme is consistent with the theoretical framework of symbolic interactionism, and was also directly relevant to the data because the themes could readily be organised into categories that related to either 'action' or 'conditions and consequences'. In accordance with the theory of symbolic interactionism, data that related to 'consequences' of action could also have been 'conditions' for action. The following excerpt from my methodological journal illustrates the value of applying an organising scheme to the data;

*11 July 2007*

*The model explaining how dignity is lost or maintained was developed by making links between categories and working out what their relationships are to each other. This involves processual rather than descriptive analysis. A theory must explain and predict and therefore go beyond the description and analysis of individual categories. This stage of analysis has enabled me to separate out process from action, and to re-categorise themes into 'doing' and 'communicating', which are the two components or elements that make up intimate care.*



Both Glaser (1978) and Charmaz (2006) have stressed the importance of using gerunds to increase theoretical sensitivity by prompting a researcher to think about actions when coding. Themes were therefore named using verbs that operated as a noun (i.e. they ended in 'ing'). Themes were organised into two categories referring to 'actions and interactions' ('doing' and 'communicating') and three categories that related to 'conditions and consequences' ('attribution of humanness' and 'meaning of intimate care') as shown in figure 6.6. These categories are described in detail in chapters 7 and 8.

<b>Figure 6.6: The organisation of themes into categories and sub-categories</b>	
<b>'Action and interaction' categories and themes</b>	
<b>Doing</b>	<b>Communicating</b>
Covering nakedness Maintaining privacy Being indiscreet Dealing with incontinence Using the toilet as a seat Waiting Washing Shaving	Chatting Being kind and caring Giving support ungraciously Being harsh Responding to non-verbal communication Infantilising
<b>'Conditions and consequences' categories, sub-categories and themes</b>	
<b>Attribution of humanness</b>	<b>Meaning of intimate care</b>
<b>Attributing humanness</b> Seeing individuality Attributing ability Having empathy Seeing the relationship as reciprocal  <b>Failing to attribute humanness</b> Objectifying Failing to acknowledge individuality Seeing people with severe and profound intellectual disabilities as homogenously different	<b>Goal oriented</b> Maintaining hygiene and health Maintaining comfort Making you presentable Following routines and rushing  <b>Experience oriented</b> Pleasurable experience

Axial coding also involves specifying the sub-categories of a category (Strauss and Corbin, 1998). Attempting to apply sub-categories from the literature to my category of 'attributing humanness' contributed to the development of this category, but ultimately the category was grounded in the data, as this journal excerpt illustrates;

*24 October 2006*

*I have tried to fit my data into sub-categories identified from the literature but have found that this has not really worked because it has not accounted for all the data. I have therefore reverted to grouping codes into themes which I have identified in the data. The influence of the theoretical ideas in the literature is still evident in this grouping.*

## **6.7 Phase six: memo writing and sorting**

Lofland and Lofland (1984) have suggested that analytical ideas can be developed through writing. Writing memos is an important technique used in grounded theory to discover ideas and increase the level of abstraction of the analysis (Charmaz, 2006). Throughout analysis, thoughts, observations and analytical ideas about the data and about the research process, were recorded in memos and in a methodological journal as they occurred. Such thoughts could arise at any time and it was therefore useful to always have a pen and notebook to hand. Definitions of themes and categories were also developed through writing and re-writing memos. Analytical ideas that arose when making field notes, reading documents and transcribing data were noted in pencil in the margin beside the relevant data, and later transferred to the memo system of MAX qda. MAX qda has a sophisticated memo system which enabled me to assign labels and colour or symbol coding to categorise different types of memos. This made it easy to retrieve all of the memos that related to a particular

issue. Memos were organised into five different categories using MAX qda's colour and symbol coding, as shown in figure 6.7, to make retrieval easy.

**Figure 6.7: Symbol coding of memos**

- 1 (!) Memos that contained the initial thoughts I had about the data at the time of observing or interviewing and at the time of transcription
- 2 (M) Reflections that I made about the possible influence of my own involvement on the behaviour of participants
- 3 (?) Ideas about possible questions to ask participants in interview
- 4 (R) Areas that needed further investigation through observation
- 5 (C) Code memos containing a provisional theme and category definition

In the later stages of analysis in this research, when the core category had become more fully integrated with the themes and categories, time was devoted to reading, writing and thinking, and during this time the theoretical ideas that had begun to emerge were made clearer and stronger. In grounded theory, memo sorting can be used as a starting point for writing (Charmaz, 2006). Memos were therefore collected together and organised logically, and became a first and rough draft of the discussion chapter of this thesis. Through writing came clarity, and also an ability to express ideas to an audience in a coherent manner. In qualitative research, analysis and interpretation never ceases, and it has been argued that concepts always remain as 'sensitising concepts' and open to revision (Charmaz, 2006). The following excerpt from my methodological journal shows that analysis and interpretation continued throughout the entire research endeavour;

*8 November 2007*

*I have continued to analyse my findings right up to writing the discussion. Reading texts related to categories has prompted further thought and clarification about my interpretation of the data.*

The credibility of the findings made in this thesis rests on the extent to which they can be considered to be robust, reliable and valid. Therefore, before moving on to describe the findings made in this study, the methods by which reliability and validity have been demonstrated are discussed in the remainder of this chapter.

## 6.8 Reliability, validity and generalisability

*'Data in themselves cannot be valid or invalid; what is at issue are the inferences that are drawn from them.'* (Hammersley and Atkinson, 1995, p223).

It has generally been accepted that *'without rigour, research is worthless, becomes fiction and loses its utility'* (Morse *et al*, 2002, online). Reliability, validity and generalisability are criteria that have traditionally been used to measure and demonstrate rigour in research that has been carried out within the positivist paradigm, and qualitative research has been criticised for failing to stand up to these criteria (Cutcliffe and McKenna, 1999; Tobin and Begley, 2004). However, the applicability of quantitative criteria for evaluating qualitative research has been questioned (Guba and Lincoln, 1981; 1985; Hammersley and Atkinson, 1995; LoBiondo-Wood and Haber, 1998). Appleton (1995) has argued that;

*'If qualitative research is to stand up to the constant barrages of positivist thinkers, qualitative researchers must be clear about how they address issues of reliability and validity within their research studies'* (Appleton, 1995, p993).

Lincoln and Guba (1981) have developed criteria for qualitative research based on the notion of 'trustworthiness'. Slight variations to their criteria have since been described, but LoBiondo-Wood and Haber (1998) have suggested that 'credibility', 'auditability' and 'fittingness' have been common themes to most

accounts. 'Fittingness' is sometimes used by qualitative researchers to relate to the quantitative notion of 'generalisability', and issues related to the generalisability of this study's findings will be discussed in more detail in section 10.3 of chapter 10.

Many qualitative researchers and commentators have persisted in using traditional quantitative terms when discussing the rigour of qualitative research. Morse *et al* (2002) have argued that 'reliability' and 'validity' are appropriate criteria for qualitative research, because the goal of all research is to produce plausible and credible explanations. They have also supported a view that there should be '*methodological coherence*' between the specific research approaches and the criteria used to judge the credibility of the research, and suggested that;

*'If the principles of qualitative inquiry are followed, the analysis is self-correcting. In other words, qualitative research is iterative rather than linear, so that a good qualitative researcher moves back and forth between design and implementation to ensure congruence among question formulation, literature, recruitment, data collection strategies, and analysis'* (Morse *et al*, 2002, online).

The methods used to ensure the reliability and validity of qualitative research must therefore be different to those used in quantitative research. Morse *et al* (2002) have also argued that qualitative research has tended to be evaluated using post hoc strategies, but mechanisms to ensure reliability and validity must be woven throughout the entire research process. The methods of; triangulation, keeping an audit trail, the presentation of unedited extracts, reflexivity, deviant case analysis, category checks, respondent validation and agreement between researchers and expert opinion, were used to ensure that the research was carried out systematically and with rigour.

### **6.8.1 Triangulation**

The reliability and validity of a conclusion is thought to be strengthened when different sources of data point to the same conclusion (Fetterman, 2001; Trochim, 2005). Each method and source of data has its own particular strengths, weaknesses and biases, and according to Smith (1975), researchers should select combinations of methods to more accurately represent 'reality'.

Two types of triangulation have been used in this study; 'methodological triangulation' which involved the use of multiple methods of data collection, including participant observation, staff interview and document analysis, and 'data triangulation' which involved obtaining data from more than one home and more than one participant.

### **6.8.2 Audit trail**

The use of an audit trail is thought to assist the reader to judge the rigour of a study (Guba and Lincoln, 1981; Morse and Field, 1996). Because qualitative research does not follow a prescribed formula, it was important to document all stages of the research, and important decisions that were made, so that they could be made explicit to the reader. Keeping a detailed audit trail in a methodological journal made it possible to produce an accurate description of the process of analysis in this chapter, and excerpts from the methodological journal have been placed in the body of this thesis, as well as in appendix 2, as evidence of the process.

### **6.8.3 Presentation of unedited extracts**

The presentation of unedited extracts from the data in the write up allows readers to make their own conclusions about the research, thereby increasing the reliability of the study (Silverman, 2001). Therefore, in chapters 7 and 8, findings are presented with unedited excerpts from the data. In addition, the use of 'low

inference descriptors' allows readers to retain good access to the words of the participants, and reduces the amount of error that would be introduced if the researcher used their own words (Silverman, 2001). The excerpts have therefore been presented verbatim and participants own terms were used as much as possible, in coding, and developing themes and categories. However, a goal of grounded theory is to progressively develop more abstract conceptual categories (Charmaz, 2006), and therefore as analysis progressed, there was a gradual shift away from the use of descriptive labels based on the participant's own language.

#### **6.8.4 Reflexivity**

In this research, the epistemological implications of critical realism, and the view that the validity of research can be improved through the application of reflexivity have been embraced and adhered to. The inclusion of a reflexive account is thought to increase the credibility and rigour of the research by detailing each reflective and interpretive decision taken and thereby promoting honesty and transparency (Koch and Harrington, 1998).

Adopting a reflexive approach helped me to understand the influence of my own biases and to offset these using the systematic techniques of analysis, such as exploring alternative explanations that were discussed earlier in this chapter. The concept of reflexivity is therefore congruent with the theoretical perspective of 'symbolic interactionism' which holds that we each possess a 'self' which allows us to communicate and interact with ourselves.

The methods used to maintain a reflexive approach were described in section 3.4 of chapter 3, and therefore will not be repeated here. In addition to these methods, memos can also be used as part of the reflexive approach, because memos '*constitute precisely the sort of internal dialogue, or thinking aloud that is the essence of reflexive ethnography*' (Hammersley and Atkinson, 1995, p192).

Excerpts from memos concerning personal feelings and subjective responses to the data have therefore also been included in the findings chapters because they influenced the decisions that were made about what to record as well as the significance that was placed on particular events.

#### **6.8.5 Deviant case analysis**

Another strategy for improving the validity of qualitative research is to search for and discuss data that is contradictory to the emerging hypotheses. The search for deviant, or negative cases, is integral to the method of constant comparison that is used in grounded theory analysis (Silverman, 2001). Clarke (2005) has objected to the idea of regarding observations as 'deviant' or 'negative', and following the teaching of Strauss, she has suggested that these cases should be thought of as indicative of a range of variation and built into the theory.

Therefore, cases which contradicted a theme or pattern were not rejected, but were built into themes and categories in order to build variation within the emerging theory. The themes and categories were scrutinised to see if they could be developed and modified to accommodate deviant cases in a manner that is consistent with the interplay between inductive and deductive analysis. Deviant case analysis led to the development of dense categories and recognition of the core category 'dignity' as being multi-dimensional and having a continuum from maintaining dignity to dignity being lost. The multi-dimensional nature of the concept of dignity is described and discussed in section 9.3 of chapter 9.

#### **6.8.6 Category checks**

Guba and Lincoln (1981) have suggested that as part of the process of analysis a number of systematic category checks should be made. Categories should be assessed for internal homogeneity which means that all items in a category



should 'look alike' and be logically related, and there should be congruency between different perspectives. When differences between categories are clear there is said to be 'external homogeneity', and this means that examples and counterexamples should 'dovetail' in a meaningful way, with little data overlapping more than one category (Guba and Lincoln, 1981). However, the data collected in this present study has been analysed within the theoretical framework of symbolic interactionism, and this means that there is some overlap between different categories, but also that this overlap is meaningful. This is because in symbolic interactionism, meaning both derives from action and influences action.

A number of additional processes were used to check the robustness of the coding system. Data assigned to each code was retrieved in MAX qda and checked to ensure that it reflected the definition that had been given to the code. Errors were also corrected, for example, if data had accidentally been coded to the wrong theme as a result of a key board or mouse error. Text searches were carried out using MAX qda and located data that had been missed during coding that could then be assigned to the appropriate code. For example, a text search was carried out for the words 'blood', 'bleeding' and 'cut', and where data had been missed it was entered into the code 'shaving'.

#### **6.8.7 Respondent validation**

Respondent validation means going back to the participants with tentative results and refining the analysis in the light of the participant's reactions (Reason and Rowan, 1981). To a certain extent this was carried out with the use of semi-structured interviews and informal conversations, and by asking staff questions about the emerging themes and categories, and then refining the themes and categories based on their responses. However, using respondent validation to check the outcome of the analysis was problematic. This was because the aim of this study was to find out about the experiences of people with severe and

profound intellectual disabilities, and as previous chapters have shown, it was not possible to ask the service users who participated in this study to give verbal accounts.

It was not thought to be appropriate to ask staff participants to validate the outcome of analysis for two main reasons. Firstly, it is thought that staff accounts about the experiences of people with severe and profound intellectual disabilities lack validity (Cummins, 2002; Mirfin-Veitch *et al*, 2004). One of the reasons for this might be that care-givers want to believe that care-receivers are positively benefiting from their care (Cummins, 2002).

The difficulty of using respondent validation was also compounded because staff had not had the opportunity to step back and reflect on what was happening, and may have been unaware that their actions and interactions led to a loss of dignity. Furthermore, staff may have a vested interest in not questioning the quality of care in an environment because they are part of that environment (Ryan and Thomas, 1987). Merton (1957; 1968) has suggested it is where the attention of the researcher has shifted from the 'plane of manifest' to the 'plane of latent' functions that they have made their distinctive and major contribution. Latent functions are generally unintended and unrecognised social and psychological consequences and therefore, their findings represent greater departures from common sense knowledge (Merton, 1957).

Secondly, the theory that emerged from this study was related to a sensitive issue about how dignity is promoted. Hammersley and Atkinson (1995) have discussed the ethical issue of taking findings back to participants which might be perceived as critical. This could lead to a hostile reaction and be damaging to the relationship with the researcher, and also with the entire research community. However, it would have been of value to seek validation from the people with severe and profound intellectual disabilities who experienced intimate care, and

not being able to do this had implications for the validity of the study, which will be addressed in section 10.2.2 of chapter 10.

#### **6.8.8 Agreement between researchers and expert opinion**

Findings are thought to be more reliable the more agreement there is between researchers or with experts and colleagues in the field (Hammersley and Atkinson, 1995). Sections of raw data were therefore given to research colleagues who were asked to carry out open coding. This was done without providing any indication of the themes that had been identified in my own analysis. Colleagues were also asked to make notes of anything that struck them as important or interesting about the data. I found a high degree of agreement between researchers, and this enabled me to cross-validate my findings. Furthermore, throughout all stages of this research, my work was closely monitored by my supervisor who was able to offer a second opinion on the conclusions that I drew from my findings. Tentative findings were also presented to professionals working in the fields of intellectual disabilities and adult nursing. Discussions in these contexts were valuable for providing alternative interpretations of the data, offsetting researcher bias and increasing the validity and reliability of the findings (Slevin and Sines, 1999).

### **6.9 Summary and conclusion**

This chapter has provided a detailed explanation of how the data was systematically analysed using approaches taken from ethnography and grounded theory. 'Dignity' was identified as a property of all the themes, and in line with symbolic interactionism, this was interpreted as being significant in terms of developing a theoretical understanding of how people with severe and profound intellectual disabilities experienced intimate care. Dignity was therefore the central phenomenon around which all themes and categories were organised, and was subsequently referred to as a 'core category'. Themes were organised

into two categories which related to 'actions and interactions' in the way that intimate care was carried out and these were named 'doing' and 'communicating', and two categories which related to the 'conditions and consequences' for dignity, and these were named 'attribution of humanity' and 'meaning of intimate care'. The next chapter describes the core category 'dignity' and the 'action and interaction' categories named 'doing' and 'communicating'. The categories related to 'conditions and consequences' will be described later in the chapter 8, and a detailed and theoretical discussion of the findings will be presented in chapter 9.

## **Chapter 7: Findings 1**

### **7.0 Introduction**

In this chapter the core category 'dignity' is described, before moving on to give an account of the themes that comprised the categories of 'doing' and 'communicating'. Excerpts from the data are included to illustrate how dignity was either maintained or lost through the way that intimate care was carried out, and the weight of evidence presented here reflects the weight of evidence found in the data. Excerpts have been taken from observation notes, interview transcripts and documents collected throughout field research at the two homes, and illustrate that categories were grounded in the data.

### **7.1 Dignity**

The action categories 'doing' and 'communicating' comprised themes that captured recurrent patterns of interaction in the way that intimate care was carried out. From an early stage of analysis, it was evident that these themes related to the concept of 'dignity', and that they revealed variation as to the extent to which dignity was maintained through the different ways that intimate care was delivered. Furthermore, it appeared that in some respects an interaction could be interpreted as dignified, whereas in other respects the same interaction could be interpreted as undignified. This highlighted the need to examine the concept of dignity in more depth and, as explained in the previous chapter, to include the literature on dignity as a source of data.

Johnson (1990) has suggested that there has been a tendency to assume that health care staff share an understanding of what dignity means. However, researchers have suggested that dignity probably means different things to different people (Johnson, 1990; Fenton and Mitchell 2002; Matiti and Cotrel-

Gibbons, 2006; Carnaby, 2006). A standardised understanding of dignity is essential for the concept to be communicated, researched, used in practice, and used to generate theory (Haddock, 1996; Shotton and Seedhouse, 1998).

Numerous attempts have been made to define dignity, and Franklin *et al* (2006) have reviewed fourteen studies published between 1994 and 2005 that have used different theoretical and empirical approaches to study dignity from a nursing perspective. However, having examined the data collected in this present study, and carried out wider reading on dignity, I have found that none of the approaches used to define dignity have adequately accounted for the complexity of the concept; although each had something to offer as part of an emerging picture.

A process of concept analysis was therefore used to define dignity for the purposes of this thesis. This process was described in section 6.5 of chapter 6, and involved a systematic review of the theoretical, philosophical, psychological and theological literature to answer fundamental ontological questions about the nature of dignity, and how dignity might affect the intimate care experiences of someone with severe and profound intellectual disabilities. These findings are discussed in detail in sections 9.3, 9.4 and 9.5 of chapter 9, but suffice to say at this point, that concept analysis led to the construction of a model of dignity (see figure 7.0). This model has incorporated the ideas of Spiegelberg (1970) and Gallagher (2004) who have proposed that dignity has two dimensions; self-regarding and 'other regarding', and Shotton and Seedhouse (1998, p247) who suggested that dignity can be thought about as having different levels ranging from 'dignity maintained', to 'devastating loss of dignity'. The model also represents dignity as having multiple properties, and the sources of these properties were the data collected in this study and the research and theoretical papers referred to in appendix 23.

Figure 7.0: Model of dignity

Properties of dignity		Levels of dignity
Other-regarding Dimension	Self-regarding dimension	
Being treated like a person, not an object	Feeling like a person, not an object	<p>Maintained ↔ Lost in a trivial way ↔ Lost in a serious way ↔ Lost in a devastating way</p>
Being treated as a whole person	Feeling like a whole person	
Being treated as an individual	Feeling like an individual	
Being treated as having equal worth	Having a sense of equal worth	
Being included	Having a sense of belonging	
Being allowed control and autonomy	Having control and autonomy	
Having competencies realistically acknowledged	Having a sense of competencies being realistically acknowledged	
Not being made to feel foolish, embarrassed, degraded	Not feeling foolish, embarrassed, degraded	
Being given a state of physical, emotional and spiritual comfort	Having a state of physical, emotional and spiritual comfort	

With acknowledgements to Shotton and Seedhouse (1998) and Gallagher (2004)

As a result of concept analysis, a definition of dignity was developed for the purposes of this thesis;

*Dignity is about feeling and / or being treated and regarded as important and valuable in relation to others. It is a subjective, multi-dimensional concept, but also has shared meaning among humanity<sup>1</sup>.*

„The variations as to the extent to which dignity was maintained or lost in relation to the different properties of dignity can be seen in the themes comprising the action and interaction categories ‘doing’ and ‘communicating’, which will now be described<sup>2</sup>.

## 7.2 Doing

The first of the action and interaction categories discussed here was named ‘doing’. This category comprised of eight themes, which are identified in figure 7.1. This category concerned *the way* that activities, including bathing, showering, supporting service users to use the toilet, shaving, cleaning teeth and dressing were performed. The themes in this category refer to the actions of staff within space and time, and the approaches and techniques that they used. Each of the themes in this category will now be described consecutively.

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<sup>1</sup> With acknowledgements to Haddock (1996).

<sup>2</sup> Excerpts from observation notes are presented in quotation marks. Verbatim quotations are in “double quotation marks” [“ ”], and non-verbatim quotations are in ‘single quotation marks’ [‘ ’]. Excerpts that are from interviews can be identified because they are preceded by the name of the person being interviewed and a semi-colon [ ; ]. Staff and service users are referred to by their pseudonym for the reasons explained in chapter 4, section 4.3. It should be clear from reading the excerpts who is a member of staff and who is a service user, and clarification can be found in figure 4.1 in chapter 4.



**Figure 7.1: Themes in the categories 'doing' and 'communicating'**

Doing	Communicating
Covering nakedness Maintaining privacy Being indiscreet Dealing with incontinence Using the toilet as a seat Waiting Washing Shaving	Chatting Being kind and caring Giving support ungraciously Being harsh, belittling and bossy Responding to non-verbal communication Infantilising

### **7.2.1 Covering nakedness: 'people leave him sitting naked on the toilet'**

The first of the themes in this category is 'covering nakedness', and data in this theme referred to instances when service users were left naked during intimate care, on occasions when they could have been clothed or 'covered up'. This was an important theme because a vast amount of data was assigned to it, and it will therefore be discussed here in detail.

Although service users were never left unclothed in any of the 'public' areas of the home, it was usual for them to be naked around the time when intimate care was provided. For example, service users were left completely naked whilst being shaved or waiting to be dressed, as the following observations illustrate;

*Simon is sitting on the toilet with no clothes on whilst being shaved.*

*Elaine sits on the chair in her dressing gown. Gemma asks her to stand up and take off her dressing gown and then sit back down again with no clothes on.*

*Barry is sitting on the bed naked whilst Faye looks for his clothes.*

In the observations that were made, service users were repeatedly left to sit or

stand unclothed when they did not need to be, for example, whilst the bath was being filled, and in addition, there was rarely any attempt to 'cover them up' whilst they stepped in or out of the bath or shower. In the following observation, a service user was asked to take her clothes off before the bath was ready for her to get in. The memo I wrote at the time shows how I thought the way this was done was undignified;

*"Night dress off please." Elaine takes her night dress off. Elaine still has her shoes on but is otherwise naked.*

*Memo: Instructions were short and clear and to the point. The atmosphere was tense and the interaction lacking in kindness. Elaine was undressing in the middle of the room without anything to hold onto and under Rita's scrutiny. Rita adopted a domineering and perhaps aggressive posture with her hands on her hips. How many people could take off their slippers without holding onto something? And how could this be done naked whilst maintaining dignity? I considered how this might have been done better. Perhaps Elaine could have taken her night dress off in the bedroom and put her dressing gown on. Then she could have taken her slippers off and then her dressing gown before getting into the bath.*

Only one member of staff, on one occasion was observed trying to cover up a service user whilst she was getting out of a bath, and it is impossible to know whether this was only done because I was observing. On this occasion, a towel was held up so that the service user's body could not be seen as she stepped out of the bath;

*Beth is just about to get out of the bath. Caroline says "We'll cover your blushes" and holds up a towel.*

There were few notable examples of staff attempting to 'cover up service users'

at other times during intimate care as these observations illustrate;

*Caroline keeps the towel around David whilst he moves from the bath to sit on the toilet.*

*“Dry you up and down mate, get some, uhm, get some shorts on him, just you know just so you’ve got something on.”*

Service users were also left naked whilst sitting on the toilet as the following observation illustrates;

*Sally knocks on Barry’s bedroom door and we enter. Barry is in his en-suite shower room, the door between the shower room and the bedroom is open. Barry is sitting on the toilet with no clothes on.*

This happened despite staff telling me that they recognised it may not be very nice;

*Sally: Cos it can’t be very nice for him to be naked in front of me.*

One member of staff spoke passionately about how she disagreed with service users being left on the toilet naked;

*Sharon: ...I don’t like leaving him on the toilet with no clothes on, some people do tend to do that. Well I’d leave him with his pyjama top on or something. And I’d put a bath mat under his feet or leave his slippers on so that he is warm. Uhm, if he was wet, then I’d put something on him, or put a towel over him and a towel over his shoulders so he’s covered up at least, and warm. Cos I just, I just don’t like that when people leave him sitting naked on the toilet. It winds me up.*

In the following excerpt from an interview, one member of staff pointed out that it would be easy to become desensitised to seeing service users naked;

*Sally: Well I think we all respect privacy. I mean, there are (pause) we can get a bit lackadaisical sometimes in that cos we're here and that everybody has seen it before and I mean, there, there is the risk of that.*

The suggestion that nakedness caused a loss of dignity was based on using a technique from symbolic interactionism called 'sympathetic introspection' which was discussed in section 2.14 of chapter 2. This involved imagining how a person might feel, and the responses that immediately came to mind included; embarrassment, shame, helplessness, vulnerability, inferiority, coldness and dirtiness. However, it was important to remember that not everyone would respond in the same way and to avoid taking one particular stance to the data analysis, I used the 'flip flop' technique of Strauss and Corbin (1998), which was described in section 6.3 of the previous chapter. This involved considering a range of possible feelings that people might have about being naked in the context of receiving intimate care. Responses might include feelings of freedom, liberation, pride (in one's body) or indifference. However, literature reviewed on experiences of intimate care, in section 2.8 of chapter 2, arguably suggests that an overwhelming majority of people would experience being naked in front of others, in the situations described in this chapter, as undignified.

In order to analyse themes in more depth, a method of enhancing theoretical sensitivity can be used to compare the area of study with different social situations (Strauss and Corbin, 1990). In this study, this involved comparing intimate care to other social situations in which one person might be naked in the presence of someone else who is clothed. Such situations include medical examinations, giving birth, having a massage and receiving beauty treatments.

However, these examples are fundamentally different to intimate care, because

they are atypical or infrequent, whereas the experience of intimate care for people with severe and profound intellectual disabilities is something that they may have little control over and have to endure on a daily basis throughout their entire lives. There may also be a difference in the level of discretion that is shown by the care-giver or professional. For example, during massage, beauty treatments and medical examinations, it is common practice for the practitioner to be discreet by averting their gaze and their attention away from a naked body, and ensuring that the parts of the body that do not need to be exposed are kept covered up at all times. For example, nurses are trained to use towels to cover up a patient or client whilst giving a bed bath so that only the parts of the body being washed at any one time are exposed (Lawler, 1991). Similarly, massage therapists are also trained to cover up parts of the body that do not need to be exposed during a massage.

The failure of some staff to keep service users 'covered up' at certain times is evidence that within intimate care, the body is not always regarded or treated as being private. Evidence for the disregard for privacy was also found in the theme, 'maintaining privacy', which is outlined next.

### **7.2.2 Maintaining privacy: '*Everybody has seen it before*'**

These data coded in this theme concerned the extent to which keeping doors shut, and knocking on doors before entering, maintained privacy during intimate care. The field notes showed that doors were shut whilst intimate care was being carried out and staff always knocked on the door before entering as this observation illustrates;

*Caroline leaves the bathroom for a few minutes and comes back and knocks on the door before entering.*

The following excerpt from an informal interview shows that a reason for keeping

doors shut was to maintain privacy;

*Joan told me that she does think that privacy is important and gave the example of 'making sure that doors are closed'.*

However, when data coded in this theme were analysed within their context, it became apparent that the extent to which privacy was maintained by complying with this 'unwritten rule' was limited. This was because keeping doors shut during intimate care did not stop other staff or service users from entering the room, as the following observation illustrates;

*David is in the bath and is being supported by Caroline. Rita knocks on the door; enters and immediately sprays air freshener.*

This illustrates that although staff always knocked on the door, they did not usually wait for a response before entering. A service user was therefore sometimes naked when another person entered, and no intention was ever shown to cover up the service user at these times.

The following excerpts from informal interviews suggest that this was not thought to be a problem, and also that it was felt by staff to be important to be able to enter during intimate care for the service users' safety;

*Joan thought that it was okay for other staff to knock and enter the room during intimate care because they probably wanted something important.*

*Caroline tells me that some people say that she should lock the bathroom door [during intimate care], but she is worried about what would happen if she slipped over and it took a long time for someone to get in. She said 'Anyone can walk in on me at any time. I've got nothing to hide'.*

There were also a number of occasions when other service users entered the bathroom whilst someone else was bathing or on the toilet. Although they were asked to leave the room, the invasion of privacy did not appear to cause any particular concern to staff as illustrated by the following comment made during an informal interview;

*Caroline tells me that they all do it [walk in on each other]. 'It's not that they haven't got rights, just because they have got learning disabilities. That's not what I am saying.... They're not doing it for any malice, not to ogle'.*

In conclusion, this theme has suggested that although an intention behind keeping doors shut and knocking before entering was to maintain privacy, the manner in which these activities have been carried out may not have been successful in doing so. This could have been for a number of reasons that will be further discussed in part two of chapter 9.

### **7.2.3 Being indiscreet: '*Simon was shitty this morning*'**

In this theme personal comments were made, about service users' bodies and body functions, to me and other staff, and in the presence of other service users. A common example of this was when attention was drawn to a person's incontinence in the manner illustrated by the following observation;

*Lorraine, Caroline and I are in the living room and Lorraine tells Caroline that Elaine was wet twice yesterday. Elaine and other service users are in the living room at the time.*

At times, indiscretion could have been explained by the need to communicate with other staff in order to provide appropriate care. However this did not explain, or account for, use of what I have interpreted as 'degrading language'; such as

when;

*Night staff told the day staff that "Barry was shitty this morning".*

*James and Sally were talking in the kitchen and James told Sally that "there was fucking loads of it" [referring to James' incontinence that morning].*

It is possible that an assumption was made that a service user could not understand what was being said, and therefore that such degrading comments would not cause harm. Staff might also have become so accustomed to this aspect of their work that they had become desensitised to its intimate and personal nature. This could also be seen as using colloquial language in a jovial and light hearted way, which might also have been a way of coping with their own embarrassment and making light of a difficult part of their work.

#### **7.2.4 Dealing with incontinence: 'It's very, very nasty'**

This theme is about the different ways that incontinence was dealt with and how this might have impacted on dignity.

On one occasion, a female member of staff asked a male staff member to help her take one lady to the toilet. I asked the female staff member about this and the following excerpt from an informal interview suggests that she had only thought about the implications of this from the male staff member's perspective and not from the female service user's perspective;

*At 4.20pm Gemma asks a male agency staff to help her take Mary to the toilet. I ask her if it is ok for a man to support Mary to use the toilet. Gemma tells me that it is, if no female staff are available, and that because the other female staff member is in the kitchen preparing dinner*



*she is not supposed to help with intimate care. Gemma also tells me that it is ok 'as long as the man does not mind'.*

There were differences in the way that incontinence was managed in the two homes. In one of the homes, service users who were incontinent wore pads at all times, whereas in the other home, there was resistance against the use of pads because some staff did not think it was appropriate;

*Staff are thinking about "padding him" at night. Sally tells me that Faye thinks that this would be 'regressing him'.*

*Barry gets out of bed and Faye says "You've got a pad on! Why have you got a pad on?"*

However, it was acknowledged by other staff that the alternative to wearing pads could be being wet, and Sally told me that she thought it was;

*'not nice to be wet at night'.*

One male service user was allocated to a 'special seat' which had a washable cushion;

*Sharon: Yeah the one armchair, that's why he always sits there....this is Barry's seat (laughs) but there's a reason, it's a special incontinent one, it's all plastic, uhm yeah.*

No one else was allowed to sit in that seat and Barry rarely sat anywhere else. This observation led me to consider what effect having a 'special seat' had on maintaining his dignity, and also on allowing this gentleman opportunities to make choices about where he wanted to sit and having variety in where he sat.

One way that the more physically able service users were supported to be independent was by dressing them in clothes they were able to put on and take off by themselves, as illustrated in the following observation;

*Caroline comments on Beth's new trousers and that they are a bit big on the waist but this means she can pull them down herself.*

However, when service users wore trousers that had fastenings they could not manage for themselves, they would come out of the bathroom and into communal areas of the home without their trousers done up, and with their underpants showing;

*Elaine came down the hallway with her trousers pulled down (having just used the bathroom).*

The different attitudes and practices for dealing with incontinence have suggested that there may be different ways of promoting dignity. For example, the issues around the use of pads suggested there were tensions between different ways of promoting dignity. It could have been seen as more dignified to encourage independence and treat someone in an age appropriate way, but this may have been at the cost of maintaining their comfort and hygiene.

#### **7.2.5 Using the toilet as a seat: 'sit on here to get dressed'**

In this theme, service users in both of the homes were asked to sit on the toilet, either with the lid up or down, whilst having their teeth cleaned, being shaved, washed, dried or dressed;

*Simon sits down on the toilet. Sharon tells him that she is going to do her teeth.*

The affect of sitting on the toilet, to have aspects of intimate care carried out, on a person's dignity could be debated, and may only cause dignity to be lost in a relatively trivial way, if at all. However, whilst sitting on the toilet, service users were also usually naked, and earlier in this chapter it has been argued that being naked in the presence of other people is likely to be an undignified experience for the majority of people in western cultures.

Staff appeared to use the toilet as a seat for convenience. However, most staff in one home always tried to brush one gentleman's teeth on the toilet, knowing that he preferred to have his teeth cleaned in the bath, and also that it was easier if carried out in the bath. This might have suggested that using the toilet as a seat had become a ritualised aspect of practice in the sense that it was done without thinking.

Another issue with using the toilet as a seat was that service users were not always given the opportunity to sit on the toilet in private to urinate or defecate, without a member of staff doing something to them, as the following observation illustrates;

*Gemma asks Elaine to move onto the toilet saying "Would you like to sit on here to get dressed. If you want to have a pee you can have a pee, yeah?"*

As another example, one gentleman always waited for staff to enter his room before getting out of bed, and the first thing that he did was to go to his en-suite shower room and sit on the toilet. His pyjamas were taken off straight away and his teeth immediately cleaned. Occasionally he was left for a few minutes to sit on the toilet whilst staff were busy doing something in his bedroom. However, the door to the en-suite would be left open, and he was therefore never given any privacy to urinate or defecate.

It was possible that sitting on the toilet for other purposes than actually going to the toilet could lead to difficulties in associating the toilet with urinating or defecating, and this could potentially contribute to incontinence. Problems with incontinence also increased when service users were left waiting to be taken to the toilet as can be seen in the following theme, 'waiting'.

#### **7.2.6 Waiting: *'Left him too long, he might have wet the bed by now'***

This theme is about how service users sometimes had to wait for intimate care, and the impact that 'waiting' could have had on their dignity. For some service users, guidelines had been written which detailed the support that was needed with 'toileting'. At one of the homes, the stated aim of the guidelines was for the service user;

*'TO REMAIN CONTINENT THROUGHOUT THE DAY, MAINTAINING HIS HEALTH, DIGNITY AND INDEPENDENCE'.*

One of the strategies for maintaining continence was to take service users to the toilet at regular times, as illustrated in an extract from one gentleman's support guidelines;

*By asking Barry if he wishes to go to the toilet when he gets up in the morning, after each meal and mid morning/mid afternoon (10.30 and 15.00) and prior to retiring to bed.*

However, guidelines were not always acted on, and service users were subsequently left for long periods of time without being taken to the toilet. On the occasion described in the following extract from observation notes, a service user's incontinence could possibly have been prevented if the guidelines had been followed;

*At 5.45 pm David is having a cup of tea and Gemma says that she will take him to the toilet after he has drunk it. No one took David to the toilet and after dinner, at around 7.30pm I notice that David is soaking wet and I tell Lorraine who goes and changes him into his pyjamas.*

Service users might also have been left waiting because they were unable to verbalise when they needed support, or because non-verbal communication was missed or ignored as the following observation illustrates;

*It is 7.30am and Josie is reading a newspaper. I can hear Beth in the hallway making sounds. After some time Josie says that she will attend to her.*

Staff appeared to find certain aspects of intimate care unpleasant and this could have explained some of the occasions when service users were left waiting to have their intimate care needs attended to. In the following observation, a member of staff was in no rush to attend to a gentleman who has been incontinent of faeces;

*Sally tells me [as a way of explanation] that Barry is "smelly this morning" and that she is "building up to it".*

Every morning one male service user was awake and sat up in bed when staff went to help him get up, as this excerpt illustrates;

*7.45am Barry is sitting up in bed, smiling and rocking when we enter his bedroom.*

It is possible that this gentleman had wanted to get up earlier, but there were no strategies in place for enabling him to communicate when he wanted to get up,

and he was therefore powerless to have any control over this part of his life.

At times, staff did respond to service users' behaviour so that they did not have to wait, as this observation illustrates;

*Sally goes into Simon's bedroom and asks "shall we put the radio on?"  
Sally puts the radio on then starts to leave the room. Simon pulls Sally by the hand back into the bedroom. Sally says [to me] 'I am going to have to do Simon' [she was planning to support another service user first]. Sally says [to me] "he wouldn't let me go".*

However, this meant another male service user had to wait to be supported to get out of bed, and Sally explained why this may have been a problem;

*'...left him too long, he might have wet the bed by now'.*

However, efforts were made to ensure that everything was prepared beforehand so that, once it had started, intimate care ran smoothly;

*Sharon: I let him sleep in while I'm getting the room prepared.*

### **7.2.7 Washing: 'I don't like to touch it too much'**

This theme was about the way that service users were washed, and the impact this might have had on dignity. In some respects the daily bath or shower, which was a routine in both homes, could be seen as a way of maintaining dignity by keeping service users clean. However, some of the ways that this was carried out could have led to the loss of dignity. For example, in some instances, the same flannel was used to wash the anal and genital area that was used to wash the face;

*Denise wipes Barry's face and eyes with the same flannel that she used to wash Barry's body and genitals.*

*Gemma washes Mary's body and then her face.*

Some comments suggested that staff found it difficult to carry out genital hygiene, and one member of staff articulated her reluctance to touch this part of a man's body in the following excerpt from an interview;

*Sally: Well I just, I don't actually like to touch it too much but I mean I tend to you know when I am washing with a sponge I will always try and if I can make sure I clean round there and make sure it's all clean and stuff. But I mean I wouldn't do anything else to them, so, it's just generally keeping an eye.*

No member of staff was observed to wash the genital area of any female service users or to pull back the foreskin to wash a male service user's penis. In the following excerpt, a member of staff washes a service user's body, hands and face, but then asks the service user to clean her genitals for herself;

*"Are you going to do your rudy bits?" Caroline gives Beth the flannel, but Beth does not take it.*

Observations also showed that service users were not dried thoroughly in the genital area;

*After Simon has had a bath he goes to sit on his bed to get dressed.  
When he stands up there is a wet patch on the sheets.*

The apparent reluctance to wash or dry genitals may have been due to embarrassment, or because staff felt that it was an undignified intrusion on the

service user's privacy. They might also have lacked the knowledge and skills to know how to clean a man's penis. Variations in hygiene could also have reflected personal standards and cultural norms.

The following comment made during an observation suggested that one member of staff was concerned, not only to clean a gentleman who had been incontinent, but to do so in a way that maintained his dignity;

*Sally says "We've been using wet wipes" and that they are good at cleaning up. "How are we going to do this in the most dignified way?"*

*Sally tries to wash Barry and then says [to me] "I think I am going to have to do it when he gets out".*

On another occasion, I was concerned that the way washing had been carried out was far from dignified. In the following observation, an agency staff member gave one gentleman user a strip wash in the evening. This gentleman did not usually have a bath or a shower in the evening, he would normally just be changed into his pyjamas, and have his hands and face washed. I made a memo immediately after the event to record how I felt about the way that this was done;

*Adrian leads Barry out of the en-suite towards the sink; Barry is naked. Barry stands on a bath mat facing the wall next to the sink. Barry holds on to the wall. Adrian uses a soapy flannel to wash all over Barry's body.*

*Memo: I feel very uncomfortable watching this. It seems humiliating and degrading to me, to stand facing the wall naked and be washed all over. Why not have a shower or a bath if you need to be cleaned all over? Is it necessary for Barry to have a wash at all before bed? Was Adrian trying to show me that he was doing a good job by washing Barry thoroughly?*



### 7.2.8 Shaving: *'I've made you bleed again'*

This final theme in the category 'doing' concerns the potential impact of the way that shaving was carried out on dignity. This theme emerged because a number of observations were made of service users being cut during shaving, as in the following observations;

*Faye says "I've made you bleed again, haven't I".*

*There is blood dripping from his chin down on his chest. Denise puts a piece of tissue on the cut.*

However, at one of the homes, there was no problem with service users being cut because staff used electric razors. The manager of the home explained the reason for this during an informal interview;

*I asked Frank if there was a policy on wet shaving. He told me that he had not seen one. For the last ten years Frank has preferred staff not to wet shave following an incident when someone was cut. He said 'Unless the client prefers a wet shave, dry shaving is safer'.*

However, despite the risk of cutting, some staff at both of the homes said that they preferred wet shaving because it gave a closer shave;

*Caroline feels David's face for stubble whilst shaving and talks to David throughout. She tells me that she prefers a wet shave but that they are not allowed to any more.*

In the following extract from an interview, a staff member explains that a gentleman was wet shaved even though he preferred to be shaved with an

electric razor, and this suggested that getting a close shave was more important to the staff than the gentleman's comfort;

*James: Yeah, yeah and I have actually noticed that he has got a bit of a rash under there.*

*Julie: Oh*

*James: So perhaps he, you know that's what it is. He doesn't like it because it is uncomfortable.*

*James: Uhm, people could say he is a bit unshaven. If he was going out or something I might get the electric shaver out. He objects to that less. It doesn't do as good a job but obviously, I think it hurts less.*

*Julie: Mm*

*James: You know, it's not as uncomfortable.*

Some female staff said that they found shaving difficult at first, but despite my observations of service users regularly being cut, some staff believed that with practice, and after time, they had been able to master the skill of shaving and actually preferred to wet shave than to use an electric razor;

*Denise: I said 'would you please come and show me how you shave them'. Because I am just a bit frightened that I am going to cut them and I just didn't seem to, I didn't want to touch them, too, too heavily.*

*Julie: Mh. And did someone show you then?*

*Denise: Yep, Sharon came and showed me. She said, come on I'll show you'.*

*Julie: And did that make it easier?*

*Denise: Yep, yeah, a lot easier. Because I said, oh I'd rather do it with the electric razor (laugh) because I am frightened of using the other one in case I cut them (laugh).*

*Julie: And what do you use now?*

*Denise: Wet razor. It's a lot easier (laugh)*

Wet shaving may have also been unpleasant for some service users as illustrated by the following excerpt from an observation;

*Barry swallows the foam that is in his mouth.*

In summary, the themes in this category have shown that a variety of approaches have been taken to the way that intimate care has been carried out, and that some actions promoted dignity, whereas others compromised it. At times, it appeared that the physical aspects of intimate care took priority over the subjective and experiential aspects of care, and that care was carried out in a ritualised manner. This chapter now moves on to describe the second 'action and interaction' category, named 'communicating'.

## 7.3 Communicating

This category is about the effect of communication on dignity, and comprised themes that related to direct communication between staff and service users in the context of intimate care. There were six themes in this category which are identified in figure 7.1, and will now be described in turn.

### 7.3.1 Chatting: '*I talk to him all the time*'

This theme concerns the extent to which staff chatted throughout intimate care, and the impact this may have had on dignity. In the following excerpt from an interview, a member of staff explains that she regarded talking as a way of making intimate care nicer for the service user;

*Denise: I talk to him all the time that I am doing it. I say 'oh well done, well done, we don't want them nasty dentists coming and taking your teeth out' (laugh) you know 'we've got to keep them nice and clean Simon'. So I*

*say all these silly things to him and I'm smiling and then he, then he laughs. So, I always think you know that if I am smiling at him and talking to him, it keeps him happy. Whether it does...*

Some staff provided what might be described as a 'running commentary'; telling service users what was happening and what they were doing as these excerpts from observations illustrate;

*"Right, are you ready?" Sally washes Barry and gives a running commentary about what she is doing.*

*"I'm going to clean your teeth."*

*"You're going to have a wash, alright."*

*Caroline tells Beth that she is going to leave the room to get a bath mat.*

In the following excerpt from an interview, an explanation is given for why service users were told what was happening;

*Sharon: Well, I just think to (pause) well I don't know really, just to be, to speak to them constantly. I think there couldn't be anything worse especially with Barry's way of thinking because he can't see very well. If someone was to go in, rip you out of bed, throw you on the loo and then start pulling your clothes off, tackling you. I think it must be like, oh my god what's going on.*

However, not all staff spoke to service users during intimate care, as the following excerpt from an observation illustrates;

*Elaine is being supported in the bath by Rita. There is no verbal*

*communication throughout.*

In the following excerpt from an interview, a member of staff explains how she tried to prepare a service user for having his teeth brushed by telling him what would happen;

*Denise: You can't just walk up to somebody with a toothbrush and say 'open your mouth' (said aggressively).*

*Julie: Mh h. How would you do it instead? Rather than going up and saying 'open your mouth'. What would you do?*

*Denise: Well, you know I would take the toothbrush and the toothpaste and say 'I'm going to clean your teeth now, Barry, would you open your mouth please?'*

A problem was that, in giving a running commentary, service users were rarely given time to take in and accommodate what had been said to them, or to influence the interaction, as the following observation illustrates;

*Joan turns to Simon and says "here you are..." Joan puts the electric toothbrush in Simon's mouth.*

*Memo: This was done suddenly and without warning and appears to take Simon by surprise.*

### **7.3.2 Being kind and caring: 'trying to be gentle'**

In this theme, service users were spoken to in a way that demonstrated kindness, concern and care, as the following excerpts from observations illustrate;

*Sally says "Oh Barry [in a sympathetic tone of voice] "you're absolutely sodden, oh Barrykins".*

*James says "...trying to be gentle mate, you're doing well mate, very well, that's beautiful mate".*

*Denise is speaking [in a gentle tone] to Barry throughout.*

The use of terms of endearment could also have been a demonstration of care or fondness. The most frequently used was 'love', followed by 'darling', and then 'dear'. Other terms of endearment used less frequently were 'lovey', 'sweetheart', 'sweetcake', 'babe', 'honey', 'gorgeous' and 'poppet'. Some of these terms carry an implicit reference to caring for small children, and this links to the theme 'infantilisation' which will be described later in this chapter.

The frequent use of apologies may have indicated that staff cared about the infringement on the service users' privacy caused by intimate care, and that they acknowledged that service users might not have liked being touched in intimate areas, as illustrated in the following observations;

*Whilst drying Mary, Lorraine said; Sorry, I need to dry under your boobs Mary".*

*Faye wipes Barry's bottom and says "sorry Barry".*

*James is drying Simon's bottom and says "excuse me round there, sorry mate".*

The word sorry was also used when intimate care did not go to plan, as the following examples illustrate;

*"Sorry darling. I know. I'm being a right twat this morning. You're being so patient."*

*James said "sorry to mess you around Simon".*

'Sorry' was also said when staff thought that service users did not like something that they were doing. The following observation was made whilst James was trying to shave David;

*David makes quiet groaning sounds and turns his face away. "Sorry mate, you've got to have a shave I'm afraid. Sorry mate."*

This suggested that staff were concerned for and cared about the service user's experience of intimate care.

### **7.3.3 Giving support ungraciously: '*I don't get paid enough to be your slave*'**

In this theme, staff gave the impression they were being 'put out' by having to carry out intimate care. The following observations show how staff spoke in a way that could make a person feel that they were being a nuisance;

*Faye is dressing Barry. She sighs and says "I don't want to do this this morning...I'm too tired".*

*Simon leaves the room without taking his laundry with him and Sharon calls out to tell him to come back and says "I don't get paid enough to be your slave".*

*"Please don't pee on me Mary. Sometimes she pees on you when you are getting her dressed, and then you have to change her."*

*Barry has been incontinent and Faye says "thank you Mr Smith" and makes sounds like 'ah oh' and [like tutting sounds and said with a sarcastic tone].*

In the following example, one lady's teeth are being brushed by a member of staff who shows her annoyance when the lady is unable to spit out the toothpaste in the sink;

*Josie asks Elaine to spit out. Elaine finds this hard. Josie says "oh god" when Elaine does not manage to spit out properly and toothpaste runs down her chin.*

*Memo: This was said with a tone of impatience.*

Service users may also have been made to feel that they were 'lazy', as illustrated in the following observations;

*"Are you going to sit up for me so I can do your back? No? You're being very lazy."*

*Sally says "are you going to pull them down today? You're more than capable."*

*Faye says "pull your trousers down then [pause] too much to ask this morning Mr Smith".*

*'Lazy, cos you can do this yourself.'*

In the following observation, a member of staff is supporting a male service user to get out of bed in the morning and when she takes his pyjama bottoms off she finds that he has been incontinent of faeces;



*Faye makes a sound like 'ahoooh' [sounds frustrated or annoyed] and says "what have you got waiting in there? You know we haven't got a washing machine". Faye empties Barry's pyjama bottoms onto the shower room floor. Faye says "thank you Mr Smith [Barry]" and makes sounds like 'ah oh' and [like tutting sounds].*

*Memo: From her tone it is clear that Faye is not happy with Barry. She acts as though he has been incontinent to annoy or inconvenience her.*

The implicit assumption made here was that Barry should have been able to control his incontinence and known that the washing machine was not working at that particular time. Due to the severity of Barry's intellectual and physical disability, it is unlikely that he would have been able to control his bowel movements, or to understand that the washing machine was not working.

Other comments were made which also suggested an underlying belief that service users were wilfully incontinent, perhaps to annoy or irritate staff;

*Faye tells me that sometimes Barry is incontinent and says 'it depends on his mood'.*

*Sally tells me "He did this to me the other day" [incontinent in bed] and that he does this when certain night staff are on duty. Sally said that she thought Barry might not like the member of staff who was on shift last night because he always "does it to her".*

*Sally: Well I don't know how to say that because that does not sound very nice. But I think that Barry quite likes putting us out, making us do more work.*

*Two members of staff are talking in the living room where service users are also present. Lorraine tells Caroline that 'Elaine was wet twice*

yesterday'. Caroline says "Not on my shift" and Lorraine asks, "Why, what's so special about your shift?" Caroline replies "She loves me". (The suggestion being that Elaine will choose to control her incontinence for Caroline).

In contrast, on one occasion, a member of staff was observed to communicate in a way that might have reassured a service user that he was not a nuisance;

*A gentleman has been incontinent of urine and faeces overnight. He had taken a number of pairs of socks and pants to bed with him and they have all been soiled. The member of staff says that they will all have to go in the wash but that it is "no problem".*

#### **7.3.4 Being harsh, belittling and bossy: 'smelly bum'**

In this theme, service users were communicated with and interacted with harshly as the following observations illustrate;

*Faye and Sharon are watching TV in the living room with all of the service users. Simon leaves the room and Faye follows him saying "I'm going to kill him". Simon returns to the living room with Faye and five minutes later leaves the room again. Faye follows him saying "is he constipated..." Simon goes to the bathroom (where another service user is having a bath). Faye follows him again and shouts 'Simon, I'm sure [the other service user] does not want to watch you have a crap... go down to your room...'*

*Gemma touches Elaine's back to prompt her to stand up. "Come on, stand up please" (stern tone of voice). Elaine gets out of the bath. Gemma says, "Oh god. That was hard, wasn't it?"*

*Elaine is standing in the centre of the bathroom. Rita tells her to take off her dressing gown. Elaine does and puts it on the floor. Rita tells her "That's not where it goes" and gets her to hang it on the back of the door.*

*"Night dress off please." Elaine takes off her night dress, she still has her shoes on but is otherwise naked. Rita says "Shoes off". Elaine stumbles whilst taking her shoes off. She does not try to hold on to anything to do this. "Careful." Rita is stood in front of Elaine with her hands on her hips giving her the instructions.*

Some phrases that were used when speaking to service users, although often said jovially, could have been interpreted as signs of teasing, belittling, or humiliating. These terms included 'smelly bum', 'his highness', 'lazy git' and 'spotty devil.' These could have been examples of ambiguity being used as a sophisticated mechanism to laugh at the expense of belittling another, whilst being devoid of guilt by using the excuse that what was said was meant as a harmless joke.

### **7.3.5 Responding to non-verbal communication: 'I think I understand them'**

This theme concerns the amount of control that service users had over the way that intimate care was carried out, as a result of the ability of staff to interpret and respond to their non-verbal communication. This theme links to the theme 'waiting', described earlier in this chapter, in which staff sometimes responded to behaviours they interpreted as indicating that a service user needed support, but other times did not.

In the following example, a member of staff waited for a service user to go to her room as an indication of her being ready to begin intimate care;

*Elaine said that they should go to the bedroom to get Beth's dressing*

*gown. Beth was twirling in the hallway and biting her hand. Elaine waited for Beth to move. She did not try to make her go to her room, only giving occasional suggestions and verbal prompts.*

*Memo: I have been struck by the amount of patience that Elaine has shown.*

However, sometimes, even when service user's behaviour was interpreted as being indicative of a meaningful choice, it was ignored;

*Joan: But even though he doesn't want you to do it, but you still do it [cleaning teeth or bathing].*

In the following example, Denise interprets Simon's behaviour to mean that he wants to have his teeth cleaned, but instead of cleaning his teeth, she asks him to get undressed and sit on the toilet;

*Denise says "do you want to go to the toilet, darling". Simon takes his toothpaste from the shelf. Denise says "Oh, you want me to do that". Denise tells Simon to get undressed first. Simon claps his hands. Simon takes his clothes off with help from Denise. Denise encourages Simon to sit on the toilet but Simon stands in the bathroom slapping his thigh and chest. Denise says "I wish you wouldn't keep hitting yourself".*

In the following excerpt from an observation, Josie interpreted David's scratching as meaning that he needed 'private time'. At the time I questioned her interpretation and wondered if there might be another reason why David was scratching, as the memo that I wrote at the time illustrates;

*David got undressed with help and got in the bath quickly. David started to scratch his genital area immediately. Josie said "can you not do that in the bath" and moved his hand away. "I'll give you some private time in a minute." David continued scratching. Josie then said "Having said that we're in quite a rush this morning".*

*Memo: This was responded to as an undesirable behaviour (perhaps because it was interpreted as a sexual behaviour, or seen as a dirty behaviour). However, it could be that David was itching. David wears a pad and so this is probably the only chance that he gets to touch himself.*

It is possible that Josie was trying to protect David's dignity by not letting him touch himself in front of her. However, perhaps it would have been more dignified to leave him to have some private time in the bath because this was only opportunity he had to touch his genitals as the rest of the time he wore pads.

### **7.3.6 Infantilising: 'It's like doing your own or your child's personal care'**

This final theme in the category 'communicating', concerns the effect of speaking to service users like a child or baby, as in the following examples, on dignity;

*Faye goes into Barry's room and says "what are you up to?"*

*Memo: The tone is one which would be used when speaking to a child.*

*James makes sounds like 'huhu' and 'brbrbr' whilst drying Simon.*

*"Who's tickling you Mary? Naughty, naughty Gemma." Mary splashes in the bath and there is close and playful interaction.*

In an interview one member of staff describes how she communicates with a service user by saying 'silly things';

*Denise says 'oh well done, well done, we don't want them nasty dentists coming and taking your teeth out (laugh) you know we've got to keep them nice and clean Simon. So I say all these silly things to him and I'm smiling and then he, then he laughs'.*

The tendency to speak to service users like children, and to use child like language, was particularly noticeable in the words used to refer to intimate parts of the body and body products. Some of the phrases used were;

*'Are you going to do your rudy bits?'*

*'Lift up your bum bum.'*

*'Dry your bits and bobs.'*

Talking to adults with severe and profound intellectual disabilities could be interpreted as infantilising. This was understandable because providing intimate care for small children is seen as normal, and may therefore be a useful reference point for staff to work from. In interviews, some staff spoke about how their experiences of caring for children helped them in carrying out intimate care;

*Julie: Okay. So how do you think that you have known and worked out what you do have to do when you are giving personal or intimate care?*

*Sally: Erm, well, it's one [firstly] from doing it for myself and maintaining my own personal care and making sure I'm clean and tidy and my children.*

*Joan: Uhm, obviously, like I said, you, it's like doing your own personal care or your child personal care. You know, but this, you do it on an adult.*

At other times staff spoke to service users using sophisticated language, and the following excerpt shows that on one hand James might have been trying to demonstrate respect by using 'ordinary', 'age appropriate language', but on the other hand he is scolding the service user in a way that a parent might tell a child off;

*10.28am James goes into the bathroom whilst Simon is in there. James tells Simon off saying "how many times have I told you, I can't impress on you enough. It's not something people play with. It's not like in the bath.*

This member of staff might have been trying to show respect by talking to the service user in the same way he might talk to someone who did not have an intellectual disability. However, a view could also be taken that using language a person is unable to understand fails to take account of that person's abilities and developmental level, and in this way the person is not being seen as an individual. This issue is discussed further in section 9.2 of chapter 9.

## **7.4 Summary and conclusion**

To summarise and conclude, this chapter has described the core category of dignity and the themes that comprised the two action and interaction categories of 'doing' and 'communicating'. The data excerpts provided are a sample that has been selected to illustrate the theme. These data highlight the variation in the extent to which dignity has been maintained or compromised in relation to the way that intimate care has been delivered, and in relation to the way in which staff members have communicated with service users throughout intimate care. The next chapter progresses to examine the 'conditions and consequences' categories that have provided possible explanations for why dignity was at times maintained, and at others compromised.

## Chapter 8: Findings 2

### 8.0 Introduction

The previous chapter has given an account of the categories that described the actions and interactions involved in carrying out intimate care, and that were related to dignity. The categories described in this chapter comprise the themes that concern the 'conditions for and consequences of' dignity. These were the categories that could offer an explanation for the loss or maintenance of dignity and were named, 'attribution of humanness', 'meaning of intimate care' and 'resources and skills'<sup>1</sup>. In this study, the focus of analysis was on the first two of these categories because they could be examined and understood within the theoretical framework of symbolic interactionism that has underpinned this research.

Within the theoretical framework of symbolic interactionism, people are thought to act towards objects based on the meaning that the objects have for them. This implies that, the way that intimate care was delivered in this study would have been influenced by the attitudes that staff have towards people with severe and profound intellectual disabilities, and also the meaning that intimate care has for them. Attitudes and meanings are also derived from interaction, and meanings are therefore both conditions for, and consequences of action. As has already been stated in section, 6.6 of chapter 6, the 'conditions and

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#### <sup>1</sup> Resources and skills

This category suggested that resources were needed to ensure that staff had the necessary time, equipment, and a suitable environment to carry out intimate care with dignity. Staff also needed certain skills to deliver care and interact with a service user in a way that maintained their dignity. This category has not been included in this chapter because, within the theoretical framework of symbolic interactionism, analysis was focussed at the interactional level. However, the category is relevant for understanding the reasons behind staff actions and interactions, and for explaining the likelihood of dignity being maintained. The category was therefore included in analysis, and an account of the themes that comprised the category can be found in appendix 25. These issues are also discussed in chapter 10, in relation to the limitations of symbolic interactionism as a theoretical framework and the implications of this research for practice, policy and further research.



consequences' categories, of 'attribution of humanness' and 'the meaning of intimate care', were not pre-imposed on the data, but emerged from analysis and were therefore grounded in the data. This chapter commences by describing the first of these categories, 'attribution of humanness'.

## 8.1 Attribution of humanness

The themes in this category suggest that the ways staff interacted and spoke with service users, revealed something about their perception of, or attitude towards the service user in terms of whether they were regarded as being 'fully human'. This category comprises two sub-categories named; 'attributing humanness' and 'failing to attribute humanness', and these sub-categories comprise a further seven themes which are listed in figure 8.1.

<b>Figure 8.1: Sub-categories and themes in the category 'attribution of humanness'</b>	
<b>Attributing humanness</b>	<b>Failing to attribute humanness</b>
<ul style="list-style-type: none"> <li>• Seeing individuality</li> <li>• Attributing ability</li> <li>• Having empathy</li> <li>• Seeing the relationship as reciprocal</li> </ul>	<ul style="list-style-type: none"> <li>• Objectifying</li> <li>• Failing to acknowledge individuality</li> <li>• Seeing people with severe and profound intellectual disabilities as homogenously different</li> </ul>

The following section describes the four themes in the sub-category 'attributing humanness'.

### 8.1.1 Attributing humanness

In this sub-category, the four themes; 'seeing individuality', 'attributing ability', 'having empathy' and 'seeing the relationship as reciprocal' suggested that staff

regarded service users as being human beings; just like themselves.

#### **8.1.1.1 Seeing individuality: *'he is a little individual and we are getting to know him better'***

In this theme, data suggested that staff saw people with severe and profound intellectual disabilities as individuals with unique personalities. This was evident from the way staff actively interpreted non-verbal behaviour as being indicative of intentional communication, or of a person's likes and dislikes, as the following examples from observations illustrate;

*Mary groans and makes a high pitched sound a bit like crying. Lorraine says "See when you are not comfortable, that's what you do. You do tell us".*

*Sally tells me that Barry shouts if he is asked to get up to pull up his underpants and trousers separately and that Barry prefers to wait so that he only has to get up once.*

*Bella says "She's sticking her tongue out so she's happy".*

The way that staff included service users in conversations may also have demonstrated that they attributed service users with personality and individuality. Staff included service users in conversations they were having with other staff and myself, by speaking directly to the person, using their name, and also by voicing what they thought a service user might be thinking in a manner that could be described as mimicking. This involved imagining what a service user might say if they were able to speak, and saying it for them.

Including service users in conversations suggests that staff saw them as fully participating in the social exchange, and might also have been a way of showing

empathy with the service user by imagining how they might feel, as the following examples illustrate;

*Beth is in the bath and Caroline asks her to take something from her.*

*Caroline says "She says in your dreams" [as if Beth would say there is no way that she will do it].*

*Lorraine is giving Beth a bath and says; "Are you going to wash yourself Beth?" Beth smiles and laughs. Lorraine laughs and says "What's she talking about" [as if Beth is saying that this is a silly thing to ask because Beth is not going to wash herself].*

#### **8.1.1.2 Attributing ability: 'I kind of, you know think that they understand me'**

These data suggested that staff attributed abilities of thought, reason, understanding and memory to service users, at a level which was, arguably, beyond the actual developmental ability of the individual. Data in this theme included instances when service users were asked questions, or asked for their opinion, even though the service user was non-verbal and unable to give a reply, as the following examples illustrate;

*Faye supports Barry to go to the toilet and says "You've got swimming shorts on! Why?"*

*'The shower's on and ready, [pause] would you like the radio on?'*

*Sally is choosing which shirt to dress Barry in. She shows Barry a shirt and says "what do you think?"*

In the following excerpt from an observation, a service user, who is non-verbal

and has no means of formal communication, was asked to remind a member of staff to put oil in his hair;

*"If you remind me, Barry, I'll put some oil in your hair."*

These data may have suggested that staff either believed that the people with severe and profound intellectual disabilities were able to think, or that they thought it was important to treat them as if they were capable of thought, regardless of their level of intellect. Staff may have even believed that service users were more capable and intelligent than they appeared to be.

#### **8.1.1.3 Having empathy: 'I try to do it how I'd like it to be done'**

In this theme, the comments made by staff revealed empathy for the service users. Some comments also suggested that service users were thought of by staff as being 'similar to themselves', as the following excerpts from interviews illustrate;

*Joan: It's like anybody else, you know, like ourselves, sometimes you do not feel like having your bath.*

*Sharon: He just, he likes to be left alone. I suppose like we all do, he just don't want fuss.*

Some staff used an empathic approach in determining how they delivered care. The following excerpt from an interview shows that one member of staff put herself in the position of the service user, and thought about how she would like intimate care to be carried out, if she were on the receiving end of that care;

*Sally: But it is mainly, I try and do it how I'd like it to be done as well.*

Therefore, this theme demonstrates that staff saw service users as sharing a common humanity with themselves.

#### **8.1.1.4 Seeing the relationship as reciprocal: '*she loves me*'**

In the final theme of this category, the way that service users were spoken about suggested that staff believed they had developed a special relationship, and furthermore that they regarded the service user as being an active and reciprocating participant in their relationship;

*Gemma says "Don't want to get out?" Beth is standing in the bath and she steps from foot to foot. "What's stressing you? Come on, we're friends."*

*Sally tells me "Barry has always shown me affection".*

This was also demonstrated by staff's apparent belief in having a special rapport with particular service users, as the following statements made in interviews illustrates;

*Sally: I am one of his favourites I think. And uhm, he actually lets me do it. I am one of the only people who he lets do it, so I am the one who has to keep an eye on it.*

*Caroline says "We've got it down to a fine art now." 'He won't take the box for anyone else'.*

*James: You know, I do seem to have a rapport with the guys. He's looking at me, he's making eye contact, he's kind of you know responding to me in his way.*

Therefore, service users were seen as giving something back to the relationship, and also had the ability to make staff feel special.

The themes in this category suggested that staff perceived the people they were providing intimate care for as having the characteristics, that Vail (1966) and Bogdan and Taylor (1992) have argued, are considered essential attributes for humanness<sup>2</sup>. However, there were also occasions when care staff's actions or comments could have been perceived as dehumanising service users, and this data comprised the sub-category 'failing to attribute humanness'.

### **8.1.2 Failing to attribute humanness**

The sub-category, 'failing to attribute humanness', comprised three themes; 'objectifying', 'failing to acknowledge individuality' and 'seeing people with severe and profound intellectual disabilities as homogenously different'. These themes were categorised together because they all indicated that service users were not seen as being 'fully human'.

#### **8.1.2.1 Objectifying: *'I'm going to do Simon now'***

In this theme, the language used by staff suggested that service users were being spoken about as if they were objects. For example, in the following excerpts from observations, they were spoken about as if they were objects that needed to have things 'done to them';

*Lorraine says "We will put Mary on the toilet".*

*Sharon asks "shall I put Simon on the loo?"*

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<sup>2</sup> These characteristics of humanness are listed and discussed in chapter 9, section 9.9.

Referring to service users as 'them' also reduced the sense of each person being regarded as an individual;

*Sally tells me that they will "toilet them later".*

*At 7.30am staff are having a meeting to allocate tasks and there is a lengthy discussion about who will carry out intimate care for each of the service users. One person says "they've all got to be done" [impatiently, as if it does not matter who does it], and another comments that saying "getting them all done" is an inappropriate way to speak about the service users.*

This theme links with themes in the action and interaction category 'doing', described in the section 7.2 of the previous chapter, in which some data showed that staff attended to physical aspects of intimate care, but with a lack of regard for the person's subjective feelings.

#### **8.1.2.2 Seeing people with severe and profound intellectual disabilities as homogenously different: 'he wouldn't care'**

Some comments made by staff suggested that people with severe and profound intellectual disabilities were seen as being 'homogenously different', or in other words sharing common characteristics as a group, but which were different to people who do not have an intellectual disability.

One member of staff described how, before working at the residential home, she had thought that all people with intellectual disabilities were going to harm her, but that she had since found that 'they were all harmless';

*Joan: Yes, sometimes, perhaps they think they are (pause) ooh, what can I say (pause). But once you get used to them, you see that they are very,*

*very soft and gentle, you know. They are not, they are no[t] harmless, and you know they are harmless people. But at first you see them and you think that they are going to harm you or something.*

*Julie: Is that how you felt when you first came here?*

*Joan: At first, yeah.*

Another example of the way in which service users were seen as being 'all the same', was an assumption that service users would not be embarrassed about being naked in the presence of other people, even though, as the previous chapter argued, the majority of people would find this embarrassing and possibly humiliating. In one interview, a member of staff explained that he thought a service user was not embarrassed whilst being washed after being incontinent;

*James: And, h (laugh), all the time, I'm making uncomfortable conversation, he's not that uncomfortable.*

In the following excerpt from an observation, a member of staff was worried that a maintenance man would think that she has passed wind, but she showed no concern for whether the service user might have felt embarrassed;

*Faye tells me that Barry was passing wind down the hallway and that she hoped the maintenance man would not think that it was her.*

This theme, therefore indicates that at times service users were in some ways regarded as not sharing, or not being worthy of equal humanness, and were placed in a different special category of humanness, according to their label of having an intellectual disability, rather than being seen as unique individuals.



### 8.1.2.3 Failing to acknowledge individuality: *'they are all the same'*

In the final theme in the sub-category 'failing to attribute humanness', service users were also not seen as individuals with unique personalities and preferences. The majority of the evidence for this theme came from observations and interviews with one particular member of staff, who as the examples presented below illustrate, seemed to hold a belief about service users, as in some respects being 'all the same';

*Julie: And did it [the guidelines] tell you anything specific about what you should and what you shouldn't do?*

*Joan: Normally, most of them, they are all the same.*

This particular member of staff also did not think that service users were able to make choices as this excerpt from an interview illustrates;

*Julie: With things like choices, are there any sorts of choices that Barry and Simon are able to make about the way that they have their intimate care?*

*Joan: Uhm, I don't think so because they don't show anything that you can see that this is the way that they wanted to do it. So it's very difficult for me, personally to see that they have any choice of doing their personal care.*

However, the themes described in the sub-category 'attribution of humanness', suggested that these views were not shared by all staff, and the weight of evidence from data collected in this present study was towards people with severe and profound intellectual disabilities being seen as fellow human beings.

This chapter now proceeds to describe the second 'conditions and consequences' category for dignity, named 'the meaning of intimate care'.

## 8.2 The meaning of intimate care

From a symbolic interactionist perspective, the symbolism attached to the ways that intimate care was spoken about, and the ways it was delivered could have revealed something about the meanings that staff attached to intimate care. The themes in this category suggest that a variety of meanings were attached to intimate care in terms of what staff thought they were trying to achieve, and to the purpose or function that they thought intimate care served. In analysis of these data, these various meanings were grouped together into two sub-categories; 'goal oriented' and 'experience oriented', and these sub-categories comprised the five themes that are listed in figure 8.2.

<b>Figure 8.2: Sub-categories and themes in the category 'meaning of intimate care'</b>	
<b>Goal oriented: to get the job done</b>	<b>Experience oriented: to make intimate care pleasurable</b>
<ul style="list-style-type: none"> <li>• Maintaining hygiene and health</li> <li>• Maintaining comfort</li> <li>• Making the service user presentable</li> <li>• Following routines and rushing</li> </ul>	<ul style="list-style-type: none"> <li>• Pleasurable experience</li> </ul>

The weight of evidence leant heavily towards the sub-category 'goal oriented' because intimate care was spoken about and delivered more often in a way that was about achieving a tangible and visible outcome related to physical aspects of care. Because this sub-category comprised a greater number of themes, and more data was assigned to those themes, more text is devoted to describing it than the second sub-category; 'experience oriented'.

### 8.2.1 Goal oriented 'to get the job done'

This category comprised four themes; 'maintaining hygiene and health', 'maintaining comfort', 'making the service user presentable' and 'following routines and rushing'. These themes will now be described consecutively.

#### 8.2.1.1 Maintaining hygiene and health: *'You don't want to be smelly'*

In this theme, intimate care was seen as an activity which had the purpose of maintaining hygiene. The perceived importance of intimate care for hygiene is illustrated by the following comment made during an observation and an excerpt from an interview;

*"Give it a good wash, cos you don't want to be smelly."*

*Sally: I mean, uhm, (pause) even to the extent of making sure that their, (unclear) like that their penis is clean and things like that. Because obviously if you know you let anything get majorly built up there it could cause them problems and infections and all that. And it is just maintaining everything isn't it.*

Within the context of this thesis, in this theme intimate care was understood as physical care, and as part of this, it was an opportunity to examine service users physically. The following excerpt from an interview highlights how intimate care was thought to be important for physically examining service users;

*Sally: Yeah, but it is, it's just when you do the personal care you are looking out for everything. I mean I'm finding at the moment I'm looking out for Barry because he has got sort of, erm, funny raised lumps on his shoulders. And I think, erm because he has just had a wart thing taken off his face I mean obviously I am going to keep an eye on that.*

### **8.2.1.2 Maintaining comfort: ‘make you feel nice and fresh’**

In this theme, intimate care was seen as being important for physical comfort, as the following observations illustrate;

*Sally says “how’s that feel, does that feel nice and clean?”*

*“Make you feel nice and fresh when you go to bed.”*

*“I always think that your feet hurt at the end of the day, nice to have a wash:*

In the following interview excerpt, it was acknowledged that cleaning a gentleman after he had been incontinent of faeces might not be pleasant for him at the time, but was important for maintaining his comfort;

*Sally: he gets things stuck [faeces] and you have to dig about with wet wipes to get it all out and things. And he doesn’t particularly like that. But it doesn’t matter what you do, I’ve got to do that to maintain his comfort, because he could end up sore and smelly and everything.*

This suggests that staff were aware that certain aspects of intimate care might not be pleasant at the time, but that the product of the temporary discomfort caused by intimate care made it necessary to carry out that care regardless.

### **8.2.1.3 Making the service user presentable: ‘you’re looking smart’**

This theme suggests that a purpose of intimate care was to make service users presentable, as the following comments indicate;

*"Look at you, you look lovely and fresh."*

*"Get you looking decent first."*

*"Let's put some conditioner on then. Make your hair nice and shiny."*

Some staff were critical of one another if service users were not well presented, particularly if they were not cleanly shaven, or their clothes did not match, or was dirty. One member of staff told me that sarcastic comments were made if a service user had not been given a clean shave;

*James: Again, there's not really any, apart from perhaps other members of staff saying 'ooh, he hasn't had a very good shave today has he'. And sarcy little comments you get once in a while, there's no real uhm, there's no, no check list.*

Therefore, this theme, along with the others grouped in this sub-category, have suggested that staff perceived the purpose, or meaning of intimate care to be to provide physical care that had a visible outcome, rather than to deliver care in a way that gave the service user a positive experience.

#### **8.2.1.4 Following rituals and rushing: *'we have a reasonably set routine'***

The theme 'following rituals and rushing' has been included in this sub-category, because it suggested that intimate care was carried out in a task oriented way. In this theme, intimate care was sometimes carried out in a ritualistic manner, with an emphasis on visible outcomes and 'getting the job done'. This might have indicated that little thought was given to delivering care in a way that would meet an individual's particular needs.

In some respects, there was little difference in the way intimate care was carried

out for different service users, and this was acknowledged in the following excerpt from an interview;

*Julie: Are there any differences between the way that you would provide intimate care to Barry and Simon?*

*Sally: Uhm (long pause). Well it depends on, well, no I mean I try to treat them the same in that I go in there and try to get it done as quickly and as efficiently as possible to keep them happy and that sort of thing and I chat away to them and I try. The only thing is that obviously with Barry because it is a shower and not a bath I tend to just carry on going with Barry. I wash him and I do his hair and do all that kind of thing. Whereas with Simon, I like to, I leave him in the bath for a little while, while I go and pick his clothes and put his clothes out for him, so that he gets his soak and that. But other than that, not really. (Pause) I am trying to think now, you've got me thinking.*

*Julie: Yeah, take your time.*

*Sally: I don't think so because you know it's just the routine.*

Routines appeared to be used, at times in a rigid fashion and in a way that promoted order and task completion, rather than serving an individual's needs. For example, on one occasion, a gentleman had a seizure shortly after he had woken up, but instead of giving him time to recover, he was bathed almost immediately after the seizure had finished. After his bath, he went to lie down on a settee to go to sleep, but because service users always ate together, he was immediately told to get up to have his breakfast.

In the following excerpt from my field notes, I questioned whose needs were being met when service users were changed into their pyjamas a long time before they would be going to bed;

*It is very early to be ready for bed. One service user is ready for bed at*

*6.25pm, straight after dinner because he has wet himself. Is this for staff convenience or for his comfort and his own convenience? One member of staff told me that she wanted to get everything done early so that she could watch a soap opera on television.*

Bathing may also have been carried out in a ritualistic manner because all service users were given a bath or shower first thing in the morning, before they did anything else such as having breakfast, or being given a drink. This was with the exception of one lady who had a bath in the evening and the reason given for this was that she wore support stockings during the day. It was interesting to note that bathing was carried out in the morning, because paradoxically this was the time when staff said they had the least time and were often rushed. During one observation I recorded the length of time it took for one service user to get out of bed, have a bath, shave, have his teeth brushed and to be dressed. The whole process took eighteen minutes, and having seen the way that this was done, my initial thoughts were that it was rushed.

In both homes, staff told me that intimate care was also rushed when service users were scheduled to go out, as this following excerpt from an informal interview illustrates;

*"We are quite rushed in the morning when they are all out."*

Rarely was any time given for service users to relax in the bath. In the following observation, one lady was not even given any time to get accustomed to being in the bath before she had her hair washed;

*Elaine gets in the bath. Rita immediately says "Can I wash your hair please". The bath is still being filled.*

Even when service users probably demonstrated, through their non-verbal

behaviour that they wanted to stay in the bath, they were often made to finish quickly, as illustrated in the following observation;

*David lies down. Lorraine says "No, time to come out David. Do you want five minutes there to yourself? I'm afraid you'll have to come out and get ready David." Lorraine stands by the bath with the towel and David gets out. "Well done."*

If service users did not respond to verbal prompting to get out of the bath, another technique was used. In the following examples, staff pulled the plug so that a service user would be left sat in an empty bath if they had not got out;

*"Are you ready to get out? Do you want to get out? Are you coming? You haven't got time to lie in there all day today I'm afraid." Elaine pulls the plug out of the bath.*

*The bath is empty. "You're gonna get cold now. Lift up your bum bum."*

One member of staff was keen to complete intimate care quickly to give her enough time to have breakfast herself;

*Gemma is trying to figure out how get the work done in time so that she can have breakfast before 9.30 when she will have to take service users to the day centre. Jenny tells her in no uncertain terms that "service users come first". Jenny later makes a comment to me about them being concerned about getting their breakfast.*

Another activity that was often rushed was brushing teeth. When possible, I counted the number of seconds that brushing teeth lasted for and found that it generally lasted no longer than ten seconds. At Fir Tree House there were guidelines in place which stated that brushing should be carried out for much



longer. Barry had problems with his teeth and his support guidelines said;

*The toothbrush should be left on each tooth for at least 6 seconds to try to remove build up.*

In the following excerpts from observations, the way that staff encouraged service users to co-operate sounded like intimate care was being carried out for the staff's own benefit. In this data, it was as if a service user needed to help the staff in order for them to complete their job, rather than that the staff was helping the service user;

*"Get ready darling, push, push your foot in. You've got to help me."*

*Sally says 'no you, not ready, "are you going to sit up for me?" Simon sits up and Sally says "thanks Simon".*

*Denise says "well done, you are good for me".*

The themes in this sub-category have shown that intimate care was regarded, and delivered, in a way that was aimed at completing physical care, with less regard for how intimate care was experienced at a subjective level. However, the second sub-category; 'experience oriented' emerged from the finding that there were other times when due regard was given for the service users' experience of intimate care.

### **8.2.2 Experience oriented**

This sub-category emerged to account for the finding that a purpose of intimate care was, at times, seen as being about the subjective, experiential aspects of care. This sub-category comprised just one theme, named 'making intimate care pleasurable'. This theme was qualitatively very different to those described

above in the 'goal oriented' sub-category, which is why it has been appropriate to assign it to a separate sub-category.

### **8.2.2.1 Making intimate care pleasurable: 'a bit of pampering'**

In this theme, staff indicated that whilst carrying out intimate care, they were concerned to make the experience pleasant or pleasurable. In the following observation, a member of staff wants to make bathing nice for the service user by putting on the spa bath;

*"Do you want a spa bath?" Rita puts the spa on. "Is that nice?" Rita tells me that she thinks the spa relaxes Elaine. "Is that nice Elaine?"*

Other examples of making intimate care pleasurable were seen in the way staff wanted to get the temperature of the water right, and to make the environment pleasant and comfortable;

*Denise directs the shower head over Barry and says "there you go darling, not too hot, not too cold".*

*Sally: [I] keep the lights subdued because I just think that's nicer.*

The use of touch during intimate care might also have been an indication of wanting to make the experience pleasurable;

*Caroline strokes the back of her hair.*

*Elaine shampoos Beth's hair thoroughly and massages her head.*

However, observations made of touch being used to give pleasure were fairly infrequent.

Some staff acknowledged that the experience of being washed might have been pleasurable, as the following excerpt from an observation illustrates;

*Denise washes Barry with a flannel and says "is that nice?"*

Staff thought that some service users enjoyed having a bath or shower, as these comments illustrate;

*"She loves her soak in the bath."*

*"You like the water, don't you."*

*Denise: Uhm, (pause) and he seems to enjoy a shower, he loves the water running over him.*

*Sally: I think Barry quite enjoys a shower, again as long as things are happening in the right, in the right sort of order.*

One member of staff referred to intimate care as pampering;

*Denise says that she is going to give Simon a "bit of pampering".*

Support guidelines for one gentleman instructed staff to give him time to enjoy his bath;

*Simon appears to enjoy laying back in the bath with his head resting on the head rest, flicking the water with his fingers. Simon should be afforded a little time to do this before being prompted to get out of the bath.*

However, bathing and showering were often rushed, as data from the theme

'ritual and rushing' and the following observation illustrate;

*Simon sits back down in the bath and leans back. Faye pulls the plug out and says 'we have to go out this morning Simon'. Faye is standing next to the bath holding a towel and says "are you getting out Simon? You'll have to in a minute; there will be no water left."*

Although one service user was thought to enjoy bathing, he was only given a bath once or twice a week, and data collected through observations revealed that this was not for pleasure, but to clean him after he had been incontinent;

*Sally: Barry likes a bath. He has that once a week or so. He likes to have a nice soak in the bath.*

*Sally tells me that Barry is going to have a 'soak in the bath' tonight because 'he has been smelly'.*

One member of staff told me in an interview that he thought service users should be given time to enjoy their bath and that he did not understand why intimate care was rushed;

*James: I feel at times that [it] is very rushed [intimate care]. I have had staff come to me and brag about how they can come in at half seven and have the guys dressed and out of the door by nine o' clock. And I'm uh thinking, well, how long did you spend. You know. I mean why are we rushing?*

He went on to say;

*James: But there's no reason why the guys should be rushing err and something like that, not that I think you should linger but I, I spend a couple of hours in the bath (laughing).*

However, in some instances, rushing to complete intimate care might have been a way of trying to make the experience as pleasurable as possible by keeping service users 'happy'.

*Sally: I go in there and try to get it done as quickly and as efficiently as possible to keep them happy...*

One member of staff said that she did not spend long brushing teeth because she did not think that the service users liked it;

*Denise: And, (pause) I think because some of them are a bit squeamish. They don't like things put in their mouth, it is better to use an electric toothbrush. So I try not to sort of prolong it for too long.*

*Memo: There are different ways of caring. Brushing for a long time shows that care is being taken over hygiene, but brushing quickly shows that members of staff are mindful of the distress that it may cause.*

These data presented in this theme suggested that making intimate care pleasurable was important to some staff. However, because the weight of evidence was skewed toward intimate care being a 'goal oriented' activity, it seems that the subjective, experiential aspects of care were not seen as the priority when delivering intimate care.

### 8.3 Summary and conclusion

In this chapter two categories were identified which offered explanations for variation in the extent to which dignity was maintained or lost through the way that intimate care was delivered. 'Attributing humanness' and 'meaning of intimate care', are categories that have provided theoretical explanations, underpinned by symbolic interactionism, for the variability that was found in the levels of dignity within the categories 'doing' and 'communicating'. These findings have shown that seeing a person as fully human was associated with maintaining dignity, and also that perceiving the purpose of intimate care as being principally to attend to physical aspects of care, could have been to the cost of maintaining dignity. The findings described in this, and the previous chapter, have implications for theory, practice, policy and further research. These will be discussed in chapters 9 and 10.

## Chapter 9: Discussion

*'The leaving off of personal clothes serves, at a physical level to induce discomfort, humiliation and embarrassment and, at a psychological level to, represent a loss of identity and feelings of self-respect' (Wardhaugh and Wilding, 1993, p9).*

### 9.0 Introduction

The previous two chapters have described how the way that intimate care was carried out varied in the extent to which dignity was maintained or compromised. In order to understand how these findings may have affected the experience of intimate care, this chapter develops a theoretical explanation, which is grounded in the data and has been constructed in line with symbolic interactionism along with other relevant extant theory. This chapter is divided into two parts. Part one presents a theoretical explanation for the potential affect of dignity on the subjective experience of intimate care, and part two discusses possible explanations for why staff actions sometimes maintained dignity, but at others caused it to be compromised.

#### ***Part one: The effect of dignity on the experience of intimate care***

### 9.1 Introduction to part one

This research study was undertaken to answer the question 'how do people with severe and profound intellectual disabilities experience intimate care?' Chapter 2 has argued that this question could have been answered indirectly by examining the symbolism attached to the intentional and non-intentional aspects of the interaction that take place between care-giver and care-receiver. In chapter 7, themes were described which suggested that there was variation in the extent to which dignity was maintained, and furthermore,

because dignity is a multi-dimensional concept comprising a number of different properties, a single interaction could maintain dignity in some ways, but not others. Part one of this chapter therefore attempts to answer the question 'how might the presence or absence of dignity have affected the experience of intimate care and their feelings and subjective reaction to receiving care?'

Before answering this question, it was necessary to establish the validity of the interpretation that some interactions observed 'maintained dignity', whereas others 'compromised it'. The following section of this chapter therefore compares the themes that were identified in this present study with those found in previous research and literature related to dignity in health and social care settings.

## **9.2 Support for the core category 'dignity'**

A review of the literature has shown that the findings made in this present study have corroborated the findings of previous studies on dignity in health and social care settings. The interpretation made in this study of what was dignified and undignified drew parallels with the themes described elsewhere in the research literature.

For example, Walsh and Kowanko (2002) interviewed nurses and patients about their perceptions of dignity and found common themes in what both groups considered to be important for dignity. These themes included 'privacy of the body', 'being exposed', 'being rushed', 'being seen as a person', 'body as object', 'discretion', 'giving control' and 'consideration'. Other research has produced similar findings, and has identified additional factors, which were thought to be important to patients for maintaining their dignity. These factors included; keeping information confidential, being respected as a person with unique needs, acknowledging competence, not being exposed to ridiculing actions such as patronising comments, and being seen as a whole person (Johnson, 1990; Widäng and Fridlund, 2003).



Good communication, for example telling patients what is going to happen, has also been considered to be important for dignity (Price, 2004), and furthermore;

*'recognition that a person (can and does) communicate is an important source of dignity and respect' (Grove et al, 1999, p192).*

Elsewhere in the research literature it has been suggested that the ways that staff communicate and interact is important. This was emphasised by participants with intellectual disabilities in Mirfin-Veitch *et al*'s study (2004) who frequently mentioned the need for support workers to show respect and to treat those they were supporting in a friendly, caring manner. Anecdotal evidence has also found that the way people are addressed can be perceived as affecting dignity. For example, people have been humiliated by being called 'love', sweetie' or 'matey', and one army veteran found this particularly distressing and would have preferred to be addressed as 'corporal' (Duffin, 2007).

In summary, there appears to be some agreement amongst the research community that there are aspects of health and social care fundamental to the maintenance of dignity. However, the findings made in this present study, as well as those in the literature reviewed, have indicated that there are some aspects of care about which there are different ideas about what is considered to be dignified and undignified. This means that what might be dignified for one person might be demeaning for another. To illustrate this, Gallagher (2004, p595) has highlighted the subjective nature of dignity by pointing out that one older person said that *'dignity to her meant having a saucer with her cup'*.

In considering the themes identified in this present study and in the literature, three areas of interaction were noted to be particularly disposed to different, as well as sometimes opposing, ideas about what has been considered the optimum way for maintaining dignity. These areas were; the implications of

the subjective nature of dignity in relation to dependency, the speed at which intimate care is carried out, and whether an individual should be treated according to their chronological age, or their perceived level of ability, and will now be discussed consecutively.

Firstly, with regard to dependency, the literature has revealed that some disabled people have said that they have experienced indignity and shame purely in having to depend on others (Toombs, 1995; Goodall, 1992; Franklin *et al*, 2006; Buckley *et al*, 2007). However, Rock (1988) has found from her own experience as a disabled person, and from discussion with other disabled people, that independence can be seen as a variable self-concept which relates to control and choice rather than any absolute measure of competence, and therefore;

*'someone who needed to be washed and dressed may regard independence as the need to be able to decide who washes and dresses them and how it is done'* (Rock, 1988, p27).

It might therefore be concluded that loss of dignity is not an inevitable consequence of dependency, and this is because dignity can be maintained by providing opportunity for control and choice. Shotton and Seedhouse (1998) have also argued that there can be dignity in having the capability of mental strength to cope with not having other capabilities.

The second issue is related to whether or not intimate care should be carried out quickly. Cambridge and Carnaby (2002) have suggested that intimate care provides an opportunity for one to one interaction and should not be rushed, and Mirfin-Veitch *et al* (2004) have found that people with intellectual disabilities wanted their carers to take time during intimate care to interact with them. In the present study, data in the theme 'making intimate care pleasurable' has revealed that staff also recognised that some people liked to spend a long time relaxing in the bath.

However, staff in this present study also thought that there might be aspects of intimate care that service users did not like and would therefore want to be completed quickly. As a wheelchair user Vasey (1996) has described how she liked intimate care to be completed quickly and efficiently;

*'if you do not have someone who has the morning routine down to a fine art, who understands the niceties of details such as how to do your hair (and who can get through the operation quickly) then life becomes very difficult indeed'* (Vasey, 1996, p84).

*'However, it is important that the personal assistant clearly understands that the priority is to get the job done and does not expect 10 minutes chat on arrival'* (Vasey, 1996, p85).

In conclusion, the amount of time that is taken for intimate care is important for maintaining dignity, but whether it is more dignified to carry it out quickly or slowly depends on an individual's particular preferences. There is also the issue of the manner in which intimate care is carried out because there is a difference between efficiency and rushing, and the latter is probably less likely to maintain dignity. However, an added complication is that if an individual prefers an aspect of intimate care to be carried out quickly, such as brushing their teeth, this might have a detrimental effect on their health and hygiene. Having a clean and hygienic mouth also has implications for maintaining dignity in relation to how other people see them.

Finally, the issue of whether it is more dignified to treat someone according to their chronological age or to their level of ability has been widely debated within the intellectual disability literature and will be given particular attention because of its relevance to this study's findings. In this present study the theme 'infantilising' has shown that staff interacted with people with severe and profound intellectual disabilities in a mixture of infantilising and age appropriate ways. There has been no consensus of opinion in the literature about which is best.

Some interpretations of what it means to maintain dignity have led to the idea that an individual should be treated in a way that is appropriate to their chronological age because treating an adult as an 'eternal child' can be disrespectful and can also hinder an individual's development (Wolverson, 2004; Clark and Gates, 2006). This view seems to have permeated practice, because a number of studies have shown that staff have failed to adapt their communication style to fall within the understanding of a person with intellectual disabilities (Bartlett and Bunning, 1997; McConkey *et al*, 1999; Bradshaw, 2001; Healy and Walsh, 2007).

An opposing view has been taken by Carnaby (2001) and Ware (1996; 2003) who have argued that the most respectful and dignified approach to interaction involves consideration of an individual's specific abilities and disabilities. In line with this view, Bartlett and Bunning (1997) and Healy and Walsh (2007) have proposed that an optimal communication environment is one where strategies are matched with distinctive needs of individuals. If the level of communication is too low the individual can follow a 'deviancy career', whereas if it is too high the result may be an 'over-estimation career' (O'Brien and Tyne, 1981). Both of these can lead to reduced opportunity for development (O'Brien and Tyne, 1981).

The rationale for the view that communication strategies should match ability, have therefore been related to functional communication, and arguably, this means the social functions of communication such as its role in fostering a sense of belonging and social inclusion have been neglected. In support of this argument, Dennis (2003) has claimed that the role of communication in ensuring quality of life has been considered in relation to autonomy and functional communication, but neglected its other purposes such as fulfilling the need to muse, to reflect out loud and to tell stories. In addition the literature on intensive interaction highlights the importance of connecting with other human beings through communication (Nind and Hewitt, 1994).

Therefore, it is conceivable that, in this present study, when staff spoke to people with severe and profound intellectual disabilities using language that

they could probably not understand, they were attempting to treat the person with dignity by showing that they were valued as a fellow human being and included in the social group. From a symbolic interactionist perspective, this may also have a feedback effect on staff attitudes, because talking to the service user as a fellow human being encourages themselves to see them as a fellow human being, and vice versa.

Treating adults with severe and profound intellectual disabilities in accordance with their perceived abilities can mean that they are treated in a similar way to young children. Hockey and James (1993) have argued that this is a problem because people with disabilities may experience deep and personal humiliation as a result of infantilising actions. Furthermore, concern has been raised that infantilising can be regarded as a level of dehumanisation because the individual is not seen as being equal (Goffman, 1961; Sinason, 1992; Wardhaugh and Wilding, 1993). This opens the way to certain patterns of potentially risky treatment because by perceiving adults as children, care staff are able to institute regimes of control that are masked as compassion (Hockey and James, 1993). This is because it is more socially acceptable to discipline and control children than adults.

In this present study, staff were at times observed to use terminology and communication styles that would usually be reserved for interactions with children, whereas at other times they used more sophisticated language. It is possible that infantilising language was reserved for communication in the context of intimate care, because staff may not have any other models to draw upon, other than those related to parenting children (Meagher, 2006).

The debate as to whether adults should be treated in an age appropriate way, or according to their abilities, illustrates the need for dignity to be seen as a complex concept with multiple properties. An interaction that is intended to maintain dignity in relation to some properties of dignity can lead to loss of dignity in relation to others. For example, treating an adult with severe and profound intellectual disabilities as an adult may be a way of maintaining dignity by demonstrating that they are regarded as having equal worth, but

may compromise dignity in relation to treating the person as an individual and realistically acknowledging their competencies. Shotton and Seedhouse (1998) have argued that for dignity to be maintained there must be a match between circumstances and competencies, but this may be too simplistic. With regard to communication, the key to the most effective and dignified communication might be adopting a suitable language level without appearing patronising (Dobson, 2000).

It is possible that the intention behind some of the interactions that have been interpreted as undignified was to be good humoured and jovial. Whilst the positive value of humour for relieving anxiety and discomfort in nurse-patient interactions has been documented (Sumners, 1990), White *et al* (2003) have pointed out that joking and teasing may be misunderstood by the recipient and cause distress and humiliation. Joking may also function as a socially acceptable way of covering staff frustration and aggression (Martin, 1984; Manthorpe and Stanley, 1999).

By way of summarising this section, there is sufficient evidence from the literature to support the view that some of the interactions presented in the findings in chapter 7 promoted dignity, whereas others compromised it. There is also evidence to support the view that, in relation to certain aspects of care, some interactions may be considered dignified to one person, but not to another. In conclusion;

*'Dignity is a dynamic subjective belief but also has a shared meaning among humanity'* (Haddock, 1996, p925).

This section has confirmed the validity of the finding that the way intimate care was carried out in this study varied in the extent to which it maintained or compromised dignity, this chapter now moves on to address the impact dignity might have had on the experience of intimate care.

### 9.3 The ontology of dignity

Examining the ontology of dignity and defining the concept was necessary for explaining the impact that it might have had on the experience of intimate care. Such examination was also a pre-requisite for the construction of the model of dignity which is presented in figure 7.0, chapter 7. Therefore, as part of the process of concept analysis (which was described in section 6.5 of chapter 6), a review of the philosophical and theoretical literature related to dignity was conducted, and a summary of this review is now described. The discussion presented in this chapter endeavours to address philosophical questions about the nature of dignity as a foundation for determining the implications of the concept for human experience in the context of intimate care.

The term 'dignity' in the context of health and social care is usually used in reference to the experience of care. However, as already stated, there has been no general agreement on what dignity actually means, and because of its highly abstract nature, dignity has been referred to in medicine as 'an elusive concept' (Chochinov, 2002), and it has even been suggested that the concept of dignity should be rendered as useless (Macklin, 2003). It was therefore important to establish the ontology of dignity in order for it to be used to explain the experience of intimate care in this present study.

The term 'dignity' is derived from the Latin 'dignus' meaning 'worthy' (Mairis, 1994), and has been defined by the Oxford English Dictionary (2002) as '*the state or quality of being worthy of honour or respect.*' Respect has been defined as '*a feeling of deep admiration for someone elicited by their qualities or achievements*' or '*due regard for the feelings or rights of other*' (Oxford English Dictionary, 2002). Jacobs (2001) has argued that respect and dignity are two concepts that can be explained simultaneously.

The conciseness of these definitions masks the complexity of the concepts they refer to. It is the complexity of dignity and its frequency of use that has

given rise to an abundance of literature on the ontological and epistemological nature of dignity. This has addressed questions about whether it is a psychological or a moral concept, whether it is a property of an individual, or of the way that others react to him or her, and whether dignity can be affected by the way one is treated. There have been no definitive answers, and dignity is therefore a word that has continued to be used in a variety of ways (Haddock, 1996).

Various theoretical perspectives have been taken to understanding the ontological nature of dignity (Ashcroft, 2005). Haddock (1996) and Mairis (1994) are amongst those that have essentially reduced the concept of dignity to the possession of capabilities and autonomy, as these quotations illustrate;

*'Dignity is the ability to feel important and valuable in relation to others, communicate this to others, and be treated as such by others, in contexts which are perceived as threatening'* (Haddock, 1996, p925).

*'Dignity exists when an individual is capable of exerting control over his or her behaviour, surroundings and the way in which he or she is treated by others. He or she should be capable of understanding information and making decisions. He or she should feel comfortable with his or her physical and psychosocial status quo.'* (Mairis, 1994, p952)

According to these definitions, to have dignity, a person is required to have certain competencies. This makes it difficult to see how a person with severe and profound intellectual disabilities might have dignity. Because of the lack of inclusiveness in these definitions, Pullman (1999) has suggested that it is dangerous to assume that people who lack capacity for autonomous choice also lack human dignity, and therefore that dignity should not be reduced to autonomy. Instead, Pullman (1999) has taken a theoretical perspective asserting that dignity is a metaphysical concept that is possessed by all human beings.



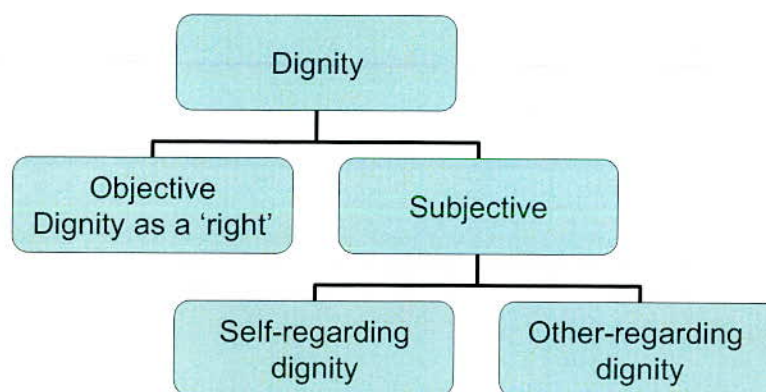
Dignity has also been discussed in terms of rights, and Dworkin (1995) has taken a deontological perspective asserting that humans have a right to dignity because they are human. Similarly, Kant (1997) has taken the view that dignity is intrinsic because all humans have value in themselves as rational beings with moral autonomy. However, Rachels (1990) has argued that the idea that human dignity is a moral doctrine based on human beings having supreme moral importance has been shattered by Darwinism, which has blurred the metaphysical and moral boundaries between man and animals. According to Rachels (1990) this means that the idea of dignity must be abandoned.

The usefulness of taking a purely deontological view of dignity, or a view that dignity is a fixed feature that everyone possesses, has also been challenged on the grounds that, if dignity is fixed, then there is nothing that can be done to take away a person's dignity (Statman, 2000). Shotton and Seedhouse, (1998) have stated that dignity is something that is experienced and sensed, and from a humanistic and experiential perspective, anyone who has had their dignity violated would reject the idea that dignity cannot be taken away. Many of the discussions on dignity have therefore, arguably taken a too narrow view by trying to reduce dignity to a single concept. For the purposes of understanding dignity in relation to intimate care, it is proposed in this thesis that dignity needs to be seen in a broader and more inclusive way, which incorporates the ideas that dignity can refer to a right, an experience and something that can be bestowed on others, as well as taken away.

A broader perspective has been taken by Spiegelberg (1970), who has distinguished between 'dignity in general', which is a matter of degree and is subject to be gained or lost, and 'human dignity', which belongs to every human being and cannot be gained or lost. Similarly, Gallagher (2004) has proposed that dignity in nursing practice should be considered both objectively and subjectively. Dignity as an objective concept is stable and enduring and is the basis of human rights, where dignity is seen as a 'value' which a person has purely because they are human. Whereas dignity as a

subjective concept includes the idea that dignity can be experienced and allows for individual differences and idiosyncrasies to be taken into account. Therefore, as figure 9.1 shows, dignity can refer to both an objective value that everyone has a right to, and to a subjective concept that is socially and individually constructed, and can be bestowed on others and experienced. In relation to dignity as a subjective concept, Spiegelberg (1970) has differentiated between dignity that is experienced as an 'inner assessment of self-worth' and 'dignity that is bestowed by others'. Gallagher (2004) has referred to these two components as 'self-regarding dignity' and 'other-regarding dignity'. The notions of self-regarding dignity and other-regarding dignity are compatible with symbolic interactionism. This is because dignity is seen as socially constructed and changeable and can come and go as a result of the way that other people see us and how this is conveyed through social interaction (Nordenfelt, 2004). The definition of dignity that has been used for the purposes of this thesis, which has been presented in section 7.1 of chapter 7, has been constructed to include both the self-regarding and other-regarding dimensions of dignity.

**Figure 9.1: Objective and subjective dignity**



Self-regarding dignity therefore refers to the experience of dignity and loss of self-regarding dignity involves the person feeling a certain way (Statman, 2000). Therefore, the self-regarding component of dignity was relevant for understanding the impact of staff's interactions on the experience of intimate care. The issue of dignity as a right was also relevant for this thesis in terms of understanding and explaining the actions of staff. This concerned whether

staff saw the person as human and therefore as having a moral right to dignity and is therefore also linked to other-regarding dignity. The issues of dignity as 'a moral right' and dignity as 'other-regarding' will be returned to later in this chapter. But first, the subjective experience of self-regarding dignity will be examined.

## 9.4 Self-regarding dignity

So far, this chapter has argued that there were certain interactions observed in this study that led to dignity being lost or maintained to a greater or lesser extent, and that the self-regarding component of dignity is relevant for understanding the subjective experience of dignity. The question of how people with severe and profound intellectual disabilities are affected by the extent to which they are treated with dignity has not been explicitly addressed in the existing literature. It was therefore necessary to examine theoretical ideas about how dignity might affect the general population, and then to consider whether these ideas applied to the lives of people with severe and profound intellectual disabilities.

Studies on dignity in health care settings have given some indications about the kinds of emotional reactions people experience when their dignity is compromised, including anger, anxiety, humiliation and embarrassment (Walsh and Kowanko, 2002; Franklin *et al*, 2006; Lundqvist and Nilstun, 2007). In another study, faecal and urinary incontinence affected emotional well-being, by leading to lowered self-esteem, shame, embarrassment and despair, and the authors argued that the negative impact this has on quality of life cannot be underestimated (Buckley *et al*, 2007).

Loss of dignity is related to humiliation and shame, and these feelings have been regarded as particularly wounding to the self-concept (Kaufman, 1985). According to Haddock (1996), dignity is connected to the self-concept and self-esteem, and Burns (1979) has suggested that self-esteem can be measured as an indication of whether a person possesses dignity. The extent

to which a person is treated with dignity can therefore not only give rise to an immediate emotional response but also have a more profound and enduring effect. Therefore, in order to appreciate the impact of dignity on subjective experience, the self, self-concept and self-esteem must also be understood.

The self-concept refers to what the individual knows about the self and what she or he feels, and self-esteem is the value that an individual attaches to him or herself (Haddock, 1996). Therefore although the terms 'self-esteem' and 'self-concept' have been used interchangeably in nursing, the view taken in this thesis is that self-esteem is a component of the self-concept (Stein, 1995). Psychological studies define the term self-esteem in ways which overlap with self-respect (Statman, 2000). However, according to Quinton (1997) self-respect is an attitude and is something that should be possessed to the same extent by everyone, whereas, self-esteem is a judgement and feeling of self-worth that can vary (Rosenberg, 1965). Self-esteem is used in this thesis to refer to 'judgement of self-worth'.

The impact of dignity on self-esteem is important because self-esteem is thought to underpin psychological and physical health (Rosenberg, 1965; Meisenhelder, 1985; MacInnes, 2006). Low self-esteem is associated with negative emotional affect (Smith and Petty, 1996), and can lead to depression and anxiety (Rosenberg, 1979). From a symbolic interactionist perspective, the findings made in this present study about the extent to which dignity was maintained or compromised, could therefore have had an impact on self-esteem, psychological and physical health.

Furthermore the idea that self-esteem is largely dependent on the way that others see us is supported from an evolutionary perspective, because self-esteem is closely linked with feelings of social inclusion (Leary and Downs, 1995). Humans do not survive in isolation and the need to belong therefore has clear evolutionary advantages. The role of self-esteem has been described in evolutionary terms;

*'It is a plain fact about human beings that their sense of personal worth is shaped to a large extent by what other human beings think about them and the treatment they receive. That individuals are able to bestow self-respect on themselves is an illusion. Humiliation takes advantage of this fact and seeks to injure self-respect by sending painful messages of subordination, rejection and exclusion. No normal human being is immune to the devastating effects of these messages.'*  
(Statman, 2000, p535)

This suggests that individuals experience a positive sense of self worth if they are thought about, or treated positively by others. Self-esteem will therefore be raised if others regard us with high esteem and treat us with dignity, whereas our self-esteem will be lowered if we are regarded without esteem and treated without dignity. Furthermore, being treated without dignity is also damaging to our relationships with the rest of humanity. Intimate care is a time when staff interact on a one-to-one basis and is therefore likely to be particularly important in the development of self-esteem.

So, the potential effect of loss of other-regarding dignity on self-regarding dignity is lowered self-esteem, and this is associated with a negative affect, which can contribute to the development of psychological and physical ill-health. In section 2.8 of chapter 2 it has been argued that people with severe and profound intellectual disabilities may experience the world differently because of the nature of their disability, and therefore the question that needs to be considered now is whether they experience loss of dignity in the same way as other people are thought to, as has been described in this section.

## **9.5 Self-regarding dignity and people with severe and profound intellectual disabilities**

The implications of the arguments made in this chapter are that for a person to experience loss of dignity as damaging to their self-esteem, they must have developed a self-concept. This section of the chapter will assert that people

with severe and profound intellectual disabilities are susceptible to experiencing damage to their self-esteem because the self emerges at early stages in the course of development and does not require advanced intellectual functioning.

This argument is based on a body of knowledge which sees social development as a process of increasing self-other differentiation. It is from self-other differentiation that infants come to grasp another person's referential intent and view themselves as a recipient of another person's actions (Müller and Carpendale, 2004). The development of the self-concept therefore requires a person to have differentiated their self as a separate entity. Different theoretical orientations have been taken to understanding the development of the self, one idea is that there is an innate potential of the self within our genetic endowment, and another that the self emerges out of interaction with the environment (Gates, 1989). The perspective taken in this thesis is consistent with symbolic interactionism which sees the self as both a social process and product (Mead, 1934).

From birth, infants are social beings (Piaget, 1963). The findings that newborns react differently to social stimuli and non-social stimuli and engage with emotional exchanges with others have been taken as evidence that the ability to differentiate self from other emerges in early infancy, or perhaps is even present from birth (Müller and Carpendale, 2004). Furthermore, the ability to impute mental states to self and others has been identified in infants as young as nine months old (Müller and Carpendale, 2004).

Neuropsychological findings support the idea that the self-concept develops at an early stage of development because the self is distributed into images and objects and is deposited at an early phase in the process of object realisation (Brown, 1999), which typically develops at around 8 months.

Therefore, although it is accepted that people with an intellectual disability are more likely to have developmental problems with regard to understanding emotions (Arthur, 2003), the possibility that they experience the same range of emotions as the rest of us in response to the way that others treat them

cannot be disregarded. This is also supported by the findings that people with profound intellectual disabilities show psycho-physiological emotional responses to stressful triggers (Chaney, 1996).

However, this does not mean that everyone's response to being treated in a certain way will be the same, and it has been suggested that self-esteem will only be damaged if the way that others treat us is incompatible with our self-concept (Goffman, 1961; Haddock, 1996; Nordenfelt, 2004; Hannover *et al*, 2006). This implies that whether or not a person experiences loss of dignity not only depends on having a sense of self, but also on having a sense of self-worth. Goffman (1961) has described 'mortification' as a process whereby;

*'the individual has to engage in activity whose symbolic implications are incompatible with his conception of self'* (Goffman, 1961, p31).

According to symbolic interactionism, whether or not we have developed a sense of self-worth also depends on the way that others see and treat us. Therefore, paradoxically, for an individual to experience loss of dignity as an insult to their self-esteem, they must have, at some time, been treated with dignity. So, if an individual with severe and profound intellectual disabilities is treated like a child then this is how they will see themselves, and, if loss of dignity is not experienced in response to an event that the majority of people would consider to be demeaning, that could be because the person does not have a sense of self-worth.

This has important implications in relation to the findings made in the present study because some staff suggested that service users did not care if they were exposed to situations that most of us would find undignified. For example when interviewed, a member of staff suggested that one service user might not care about being naked in front of other people, but nevertheless it was important to maintain his dignity;

*Sharon: Errm, and I just think it's just like respect their dignity. Really, if they're sat on the bed like, I always put a towel over his lap so that he is covered. I mean he wouldn't care if twenty people walked in but I just think it's not nice.*

This highlights the belief that some staff had in the importance of treating service users with dignity, regardless of whether they thought that failing to do so would result in the experience of loss of dignity. This is related to the objective component of dignity that refers to it being a moral right.

## 9.6 Dignity as a right

Levine (1997) has recognised that there may be instances in which a person is not aware that they have suffered a loss of dignity, and in these cases indignity is vicarious. Self-regarding and other-regarding dignity are therefore two elements of dignity that can be affected differently. Shotton and Seedhouse (1996) have discussed the moral obligation to promote dignity, and Marmont (2004) has asserted that maintaining dignity is what should dictate how we treat others.

Understanding that dignity involves other-regarding and self-regarding dimensions is therefore particularly important for working with people who have severe and profound intellectual disabilities. Arguably staff have a duty to bestow dignity, even if they think that it is not felt, because it is through treating someone with dignity that they are able to develop a sense of worth. If staff treat people with severe and profound intellectual disabilities with dignity they will also provide a model for others to follow.

Respecting the right to dignity is important because we cannot know for certain that a person does not experience loss of dignity, just because they cannot or do not communicate as the following cases from the literature highlight.



History has shown that it is a mistake to assume that people who have difficulties communicating also lack mental capacity. For example, people who have been thought at birth to have no mental capacity have later been found to have 'normal intelligence' when staff and institutional regimes have been changed, or when appropriate communication devices have been provided (Bogdan and Taylor, 1992; Sinason, 1992). Goode (1992) has also found that, a boy who was non-verbal and previously thought unable to communicate meaningfully, did make meaningful utterances that could be understood following prolonged contact. Therefore, it can be concluded that assessment of competence has generally depended on the social context and the role and background of the person describing or assessing an individual, rather than the person's actual abilities (Goode, 1992).

It is therefore important to be open-minded about the potential for people with severe and profound intellectual disabilities to have more capabilities than they are given credit for. Definitions of intellectual disabilities have often referred to pervasive deficits or delay, but Sheehy and Nind (2005 p34) have suggested that it may be;

*'more helpful to think of people with pmld as having substantial barriers to learning and participation in community life, which arise from an interaction between organic impairments and often unresponsive and unsupportive environment'* (Sheehy and Nind, 2005, p34).

This implies that we should not underestimate the impact of our actions by assuming that people with severe and profound intellectual disabilities do not understand what is being said or done. Furthermore, this chapter has argued that dignity is a right for everyone, and therefore it is a fundamental characteristic and requirement of 'care' that the person giving care does so in a way that fulfils shared concepts of self and other-regarding dignity.

## 9.7 Conclusion: part one

Part one of this chapter has argued that the literature confirms the validity of the interpretation of the findings made in this present study with respect to the kinds of interactions that are likely to maintain dignity, and the kinds that are likely to comprise it. Dignity can be maintained for different individuals in different ways depending on their unique self-concept, skills, capabilities and personal preferences. However, there are certain aspects of the way that intimate care was carried out, that could be considered 'universally' demeaning. So far, this chapter has also argued that the effect of dignity on the way that care is experienced can be on an immediate emotional level and can also have a more enduring effect on self-esteem and psychological and physical health.

In this study, dignity and indignity was brought about by the way that staff carried out intimate care. Part two of this chapter will examine theoretical explanations for the way that intimate care was carried out and how these might predict whether or not the actions of staff promoted dignity.

### ***Part two: Theoretical explanations for the maintenance or loss of dignity***

## 9.8 Introduction to part two

*'Another likely influence on staff behaviour is their perceptions of their role and of the people they are serving: Do they see them as peer or patient? Moreover, staff are paid to do a job rather than to engage in conversations'* (McConkey *et al*, 1999, p202).

The initial aim of this study was to understand the experience of intimate care from the perspective of a person with severe and profound intellectual disabilities. However, this thesis has shown that understanding the experience of receiving intimate care cannot be divorced from understanding

how care is provided, because one is largely dependent on the other. Understanding why the actions of staff sometimes maintained dignity and at other times caused it to be compromised was therefore necessary in order to offer a theoretical explanation for the experience of intimate care. This was essential for the findings made in this study to have clear implications for practice and policy and, in order for the research to have utility it was particularly important to identify the conditions under which loss of dignity is likely to occur. This chapter therefore discusses the implications of the categories 'attribution of humanness' and 'meaning of intimate care', for a theoretical explanation for the conditions under which dignity is likely to be maintained or compromised in the context of intimate care. This discussion is presented within the theoretical framework of symbolic interactionism which has underpinned this entire study.

## **9.9 Attribution of humanness**

Symbolic interactionism predicts that actions are influenced by the meanings that are attached to the objects, and the people, the action is directed to. Recognition of a person's humanity is fundamental to respect for dignity (Gallagher, 2004), and therefore in order to treat someone with dignity, a person must first be viewed as 'fully human'. Understanding what it means to view someone as human requires answering the question 'what is humanity', and this question has absorbed philosophers since men first began to think about themselves (Vail, 1966). Humanness has been defined from cultural, theoretical and spiritual perspectives and has also been defined differently throughout history.

Vail (1966) has noted that man's awareness of self is what sets him or her apart from animals, and has suggested that a number of factors are essential attributes for humanness. These include having the capacity for; emotions, thought, self-differentiation, value or self-worth, self-esteem, long-standing relationships, love, intellect, will, morality, guilt, second order emotions (such

as anxiety, hate, envy, greed, pride, despair, hope), humour and artistry, group behaviours, politics and culture, and the propensity to hurt.

The idea that humans are required to have certain attributes and competencies has led to people with severe and profound intellectual disabilities being seen as less than human. Ryan and Thomas (1987) have articulated the difficulties that some people have with seeing certain people with intellectual disabilities as sharing a common humanity;

*'They represent such an extreme of life that we wonder whether they are human at all, in any way like us. Our interaction with them seems so minimal, we wonder what the point of their existence is. Unless we perform specific care-taking tasks for them – feed, wash, change or move them – we do not know who we are for them or who they are for us. Is there any mutual identity we can establish, any reciprocity between us, and if there is, do we want to know about it?'* (Ryan and Thomas, 1987, p13)

There has been a considerable amount of literature which has argued that dehumanising attitudes have led to the mal-treatment and abuse of people with intellectual disabilities (Goffman, 1961; Vail, 1966; Wardhaugh and Wilding 1993). However, in this present study, the themes 'seeing individuality', 'attributing ability', 'having empathy' and 'seeing the relationship as reciprocal', together comprised the sub-category 'attributing humanness', and demonstrated that in the majority, these staff did view the people they were giving intimate care to as being human.

These findings could explain the actions which promoted dignity, and this has been supported by Walsh and Kowanko's (2002) findings that dignity was maintained when nurses used their shared humanity to empathise with, and understand the essential humanness and individuality of a patient.

The themes in the sub-category 'attributing humanness' also resonated with those identified by Bogdan and Taylor (1992) in a paper in which they describe;

*'the perspectives of non-disabled people that underlie their relationships with disabled people and sustain their belief in the others' essential humanness'* (Bogdan and Taylor, 1992, p280).

Based on fifteen years of research, Bogdan and Taylor (1992) have argued that the relatives of people with severe and profound intellectual disabilities and staff who worked with them spoke and interacted in a way that revealed that they recognised their disabled family member or service user as having the qualities that are essential to be defined as human. The perspectives that suggested that the disabled people were seen as fully human were; 'attributing thinking to the other', 'seeing individuality in the other', 'viewing the other as reciprocating' and 'defining social place for the other' (Bogdan and Taylor, 1992).

As in Bogdan and Taylor's study, in this present research, the lack of ability of people with severe and profound intellectual disabilities to communicate using symbols did not prevent the staff attributing the ability to think. This meant that staff treated service users as being more intelligent than they were believed to be, as this excerpt from an interview with a member of staff illustrates;

*Denise: I say, 'do you want this on, or that on?' and he doesn't really answer.*

*Julie: But you ask him anyway.*

*Denise: I ask him anyway.*

People with severe and profound intellectual disabilities were also seen by staff in this present study as being individuals with unique personalities, likes and dislikes, feelings, motives and life histories. Staff interpreted non-verbal communication and attributed a service user's feelings to have been provoked

by events that had occurred at the time. This suggests that staff thought the person with severe and profound intellectual disabilities was aware of what was going on in their surroundings and capable of expressing 'normal' human emotion. Staff also contributed towards creating personalities by highlighting unique individuality and likes and dislikes when talking about them.

Bogdan and Taylor (1992) have suggested that when looking at relationships between disabled and non-disabled people, it might appear that a relationship is one sided. However, non-disabled people in their study defined the relationship as reciprocal because both parties derived something out of it. In their study, non-disabled people said that they derived pleasure from the relationship, enjoyed the company of the person with disabilities, and benefited from having a sense of accomplishment in contributing to the other person's life. In this present study, staff also spoke about service users in a way that suggested they saw the person as reciprocating and engaging in the relationship. For example, some staff believed that they had a special relationship with particular individuals, and were proud when they thought that they were an individual's 'favourite' members of staff.

Attributing humanness has also been discussed in terms of 'defining social place', which involves seeing the person with disabilities as being part of a social group or unit (Bogdan and Taylor, 1992). Similarly, in the present study, as part of the theme 'seeing individuality', staff were described as 'giving service users a voice' to include them in a conversation. One member of staff also described how service users were 'part of a family'. This could be seen as ways of defining social place, and therefore attributing humanness.

It is also conceivable that making service users presentable, by ensuring they were clean and well dressed, was a way of encouraging acceptance by the wider community. The appearance of someone with a severe and profound intellectual disability may be important for ensuring that other people would see the person in a way that would lead them to regard that person with dignity. Stone (1962) has criticised symbolic interactionists for neglecting appearance as an important dimension of interaction. According to Overboe

(1999), from the theoretical perspective of embodiment, the body is a medium through which identity is constructed. And, from certain theoretical perspectives of social role valorisation, 'image enhancement', which may include personal appearance enhancement, is a crucial precursor to achieving socially valued roles (Szivos, 1992). These perspectives would suggest that the physical functions of intimate and personal can also serve to promote a positive self-identity and dignity.

Defining social place might therefore have been important for maintaining dignity because, as Wardhaugh and Wilding (1993) have suggested;

*'Perhaps one of the most severe mortifications for any individual is involuntary isolation, confinement away from everyday social exchanges'* (Wardhaugh and Wilding, 1993, p9).

Therefore, the way that staff spoke about people with severe and profound intellectual disabilities suggested that they saw them as being human and at times they also interacted in a way that demonstrated they were seen as being human. However, the model of dignity in figure 7.0, chapter 7 shows that dignity has various properties. These properties can be affected differently, and this means that an action which is thought to maintain dignity by attributing humanness could be perceived as demeaning in relation to other properties of dignity. For example, staff might have attempted to treat a person with equal worth by treating them as if they had 'normal intelligence', and this might have meant failing to realistically acknowledge the person's actual competencies .

Assuming that someone has capabilities that they do not have may also lead to unrealistically high expectations and misunderstanding behaviours. In this present study, some staff said that service users were 'lazy' and one service user was called a 'lazy git'. This type of remark was not dissimilar to the one that opened this thesis, which Thomas (1987) recounted from his experience of working in a hospital for the 'mentally subnormal';

*'Bathtime. Dry yourself, I'm not drying those scrawny bollocks of yours. I don't know where they've been. Do it yourself, you lazy bastard.'*

(Thomas, 1987, p39)

In the same way as was discussed earlier in relation to the ontology of dignity, a danger of equating humanness with capabilities is that some people may not possess those capabilities and therefore might not be considered to have equal human status. The view taken in this thesis is that all people, no matter what their abilities share a common humanity. Similarly, Taylor (1994 p3) has suggested that *'essentially being human is about living in the world of other people and things'*.

Bogdan and Taylor (1992) had concluded that whether or not people are treated as humans is not determined by the physical or mental characteristics of the person, or by abstract social or cultural meanings of the group, but is determined by the nature of the relationship between definer and defined;

*'What others are depends on our relationships with them and what we choose to make of them'* (Bogdan and Taylor, 1992, p291).

However, they have also pointed out that;

*'People with the same characteristics can be defined and interacted with in one way in one situation and in a radically different way in another'* (Bogdan and Taylor, 1992, p279).

This is important because the data collected in this study revealed that people with severe and profound intellectual disabilities were not always seen or treated as being fully human. This data was accounted for by the sub-category 'failing to attribute humanness'.



## 9.10 Failing to attribute humanness

The themes in the sub-category 'failing to attribute humanness' showed that there were times when staff spoke about service users in a way that objectified them, suggested that they were seen as being homogenously different to people without intellectual disabilities, or that they were not seen as unique individuals. The variation in the extent to which people with severe and profound intellectual disabilities were treated as fully human reflects the different levels of humanness that can be assigned to different individuals and groups. The devastating effects of viewing certain groups as 'sub-human', and having a life that is not worth living, has been seen throughout history. In recent history an extreme example of this was the annihilation of disabled people in Nazi Germany, which was achieved as a result of the social construction of their dehumanisation by the Third Reich (Overboe, 1999).

If staff in this present study saw service users as being 'sub-human', this seems to not have been a permanent belief, but rather a temporary perception. This conclusion has been reached because, as the previous sections has shown, there were many observations of staff interactions and comments which suggested that they did 'attribute humanness' to the people they were providing care to. According to symbolic interactionism people are able to modify and alter the meanings and the symbols they use in action on the basis, not only of their perception of the 'object' they are acting towards, but also of their interpretation of the situation. It was therefore necessary to examine the context within which denial of humanness occurred, and the literature has suggested that it could be the nature of the tasks that explains why humanness can be temporarily denied during intimate care (Menzies, 1970; Walmsley, 1989).

As found in the literature reviewed in chapter 2, section 2.12, the data collected in this present study revealed that there were certain aspects of intimate care that staff found unpleasant and did not like to carry out, as the following comments illustrate;

*James: I mean I'm feeling uncomfortable because (pause) who wants to, you know wipe a like a shitty bum. Sorry, excuse my French.*

*Sometimes it's really to be honest; sometimes it's very, very nasty....*

*Gemma says (to me) 'David is always incontinent. I hope you don't mind. It's a bit unpleasant. Hopefully he isn't today.'*

Previous research has suggested that objectifying patients in a care setting can be used as a defence against anxiety and also that it is easier to cope with the body if the person is not seen as fully human (Menzies, 1970; Chapman, 1983; Savage, 1995). Walmsley (1989) has commented that;

*'if people are seen as less human, 'transgressing normal boundaries becomes less of an issue' (Walmsley, 1989, p6).*

Intimate care has been thought to cause anxiety to care-givers because the activities it involves do not fit into any culturally normal patterns of social behaviour, and there are no social norms to draw upon when dealing with these tasks (Lawler, 1991). Furthermore, White *et al* (2003) have argued that providing intimate care may *'cut across the usual understandings of professional relationships'* and staff may therefore face difficulties in working out what their relationship should be. Intimate care is regarded as dirty work and is undervalued both within the profession and within society, and because it is a taboo subject, it is not a socially acceptable area for discussion (Wolf, 1986; Lawler, 1991). Supporting, or caring for people with intellectual disabilities is also devalued perhaps due, in part, to a shared stigma between people with intellectual disabilities and the staff who work with them (Mitchell, 2000). These factors reduce the likelihood that staff will be provided with sufficient training and equipped with coping strategies and resources that they need.

Downs (1998) has also found that staff talked about adopting a way of distancing themselves to make some intimate experiences more manageable. For example, one care worker said;

*'It's not easy to admit this, but if I'm honest, I think I cope (providing intimate care to adults) by temporarily denying their human-ness'*  
(Downs, 1998, p78).

The difficulty involved in dealing with intimacy might cause staff to temporarily suspend their view of the person as fully human. Therefore, it could be the nature of the task that leads to loss of dignity, rather than attitudes towards people with severe and profound intellectual disabilities *per se*.

It has also been argued that some aspects of care work can be experienced as threatening the dignity or prestige of the worker (Solomon, 1968).

According to symbolic interactionism, techniques that are used to establish distance between a degrading situation and the self are referred to as 'face saving techniques'. Sinason (1992) has described the reasons, from a psychological perspective, why there might be a need to maintain distance;

*'Incontinence, the lack of control of one's body orifices, from dribbling, spitting, vomiting to defecating and urinating, unites the experience of the very young, the very old and the profoundly handicapped. Fear of such loss of autonomy, the unprocessed memories of childhood helplessness, can turn into hostility, too often uniting the workers, from nurses to residential workers.'* (Sinason, 1992, p207)

*'cleaning people's mess continuously as a way of not managing to stay with their emotional experience is only the flip side of shouting at them aggressively. Being close to something that has gone wrong is a permanent reminder of the frailty of the human body and mind.'*  
(Sinason, 1992, p208)

However, neither the nature of the tasks involved in intimate care, nor the need for maintaining distance has provided a wholly adequate explanation for the loss of dignity that was found in this study. This is because actions that led to dehumanisation and loss of dignity did not correspond to the activities that staff said they found particularly difficult to deal with. For example, when dealing with continence care, staff often treated an individual with care, concern and dignity. On one occasion, a gentleman has been incontinent of faeces overnight, and when a member of staff is thinking about how to clean him she says;

*“how are we going to do this in the most dignified way?”*

Savage (1995) offered a different perspective on understanding how carers cope with intimate aspects of care. Based on findings from interviews with nurses, she suggested that having a close relationship involving reciprocity, self-disclosure and intimacy, rather than detachment helped carers to cope with intimate aspects of care (Savage, 1995).

In conclusion, in this present study, staff attitudes towards people with severe and profound intellectual disabilities, and the nature of the activities involved in intimate care may have contributed towards the extent to which dignity was maintained, but neither theories provide a sufficient explanation for the loss of dignity in a serious or devastating way. This chapter now proceeds to examine the contribution that ‘meaning of intimate care’ may have had towards explaining loss of dignity.

### **9.11 Meaning of intimate care**

In terms of explaining the actions of staff, the themes in the category ‘meaning of intimate care’ could be examined within a theoretical framework of symbolic interactionism. This is because the themes revealed that intimate care was seen as having multiple functions and gave indications of staff perceptions of their purpose in carrying out intimate care. The themes in this category were

divided into two sub-categories called 'goal oriented' and 'experience oriented'. The sub-category, 'goal oriented' comprised themes which suggested that the purpose of intimate care was regarded as being related to physical care and achieving a visible and tangible outcome, whereas the sub-category 'experience oriented' comprised the theme 'making intimate care pleasurable', which suggested that the purpose of intimate care was regarded as being related to the subjective experience.

The weight of evidence indicated that, in the main staff perceived intimate care as a goal oriented activity, which served the purpose of getting a service user clean, physically comfortable and presentable. The sub-category 'experience oriented' revealed that some staff wanted to make the experience pleasurable, but this appeared to be a secondary concern to attending to physical aspects of care.

In order to develop this into a theoretical explanation, it was important to consider how staff developed an understanding of their purpose in carrying out intimate care. Findings from interviews with managers and staff revealed that no formal training addressed intimate care specifically in either of the residential homes, and that staff had learnt what to do by 'shadowing' more experienced staff, and reading policies, procedures, risk assessments and individual support guidelines. Therefore, the social and organisational culture of the residential home may have been important in forming staff perceptions of their purpose in carrying out intimate care. Furthermore, if this perception influenced the actions of staff, the social and organisational culture might have been an important influence on the likelihood of dignity being maintained.

Therefore, in this analysis, macroscopic theories of structural functionalism, which account for how social structures and organisations can influence individual behaviour have been utilised<sup>1</sup>. According to Cuff *et al* (1998), these theories are not necessarily incompatible with symbolic interactionism, and

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<sup>1</sup> The inclusion of the category 'resources and skills' in appendix 25 also illustrates ways in which organisational and social structures may have had a bearing on dignity.

this argument will be expanded further in chapter 10, section 10.2.3.

Macroscopic theories have been used to explain dehumanisation and abuse in institutional settings, and may contribute to understanding why the actions of staff in the present study failed to maintain dignity.

Brown (1999) has argued that there has been a tendency to put too much emphasis on the individual when determining responsibility for abusive practices, and that the root cause of abuse might be the context within which the abuse takes place. Based on in-depth analysis of cases such as the Longcare Inquiry (Buckinghamshire County Council, 1998), Brown (1999) has concluded that abusive practices can be rooted at the organisational level, caused by the dynamics of the establishment and a shortfall in skilled staff. This explanation is also consistent with Goffman's (1961) analysis which subsequently has become to be referred to as 'institutional abuse'.

Goffman (1961) took a symbolic interactionist stance in his account of an asylum, but also focussed on the powerful effects of the culture of the institution. This has proved to be one of the most influential theoretical explanations for the dehumanising actions of staff working in institutions. According to Goffman (1961) when an organisation's activities are brought together in a rational plan designed to fulfil the objectives of the institution, the result is the 'warehousing' of people. Wardhaugh and Wilding (1993, p6) have also argued that the organisation plays a part in the 'corruption of care' through the 'neutralisation of normal moral concerns'.

Goffman (1961) has found that the desire for efficient management and to run an organisation as smoothly as possible can lead to people being treated as 'raw material', or in other words, as a means to an end. In these instances, people are no longer seen or treated as individual human beings and are more likely to be subjected to dehumanising practices.

In a similar vein, Foucault (1973) has described healthcare settings as institutions where residents were reduced to material and psychological insignificance by the implementation of regime. Silver and Geller (1978) have

discussed how being embedded in an organisation can transform the meaning of one's actions. By fragmenting each component of its action, and thereby obscuring the relationship between the individual's behaviour and the organisation's end goal, an individual is permitted to carry out dehumanising actions, but feel devoid of responsibility (Silver and Geller, 1978).

Dehumanisation can be an end in itself by making daily work easier for staff, because when chores are constructed in such a way as to be aimed towards non-humans, the decencies of privacy, respect and tenderness demanded by humans, becomes superfluous (Malacrida, 2005).

In relation to intimate care in social care services, this could be compared to fragmentation of the activities of the service provider, management and care-givers. Care-givers are required to carry out actions as instructed by policies which they may have had no influence in developing. This means that staff may act in terms of the goal prescribed by the organisation and feel no responsibility for any undesired or unintended effects their actions may have.

In this present study, data in the theme 'rituals and rushing' showed that, at times, intimate care was orchestrated in routines that appeared to have been put in place to meet the needs of the organisation, rather than the needs of service users. The findings made in this present study have therefore supported Dewaele and Van Hove's (2005) conclusion that Goffman's (1961) observations of dehumanising institutional practices have not been rendered out of date.

'Routine' is a word that is frequently used, but has various meanings and both positive and negative connotations (Zisberg *et al*, 2007). The value of using routines and rituals in health care settings is that they are a way of 'getting the work done' quickly and efficiently (Walsh and Ford, 1989a; Spiller, 1992). Routines are a mechanism for maintaining order, and their use has been offered as an explanation for the survival of humans as a species (Fretwell, 1982; Alasuutari, 2004). In relation to intimate care, routines could have been seen as serving useful purposes, and in some instances contributed towards maintaining dignity. For example routines can be used to ensure that support

is provided when needed and that physical needs are attended to (Miller, 1998).

In this present study, one member of staff explained the value of having a routine for intimate care;

*James: A routine is easier to remember, you know you've done everything...*

Routines also allow care-receivers to know what to expect next (Miller, 1998), and in the present study, staff believed that some service users liked their care to be carried out in accordance with a standard routine, as the following excerpt from an interview illustrates;

*Julie: Okay. And with Barry, is there anything that you think he doesn't like?*

*Sally: I'm not sure with Barry. Uhm, just the messing about bit and he likes his routine. You know erm, if you've say forgotten to give him a shave and you are asking him to get in the shower and you say can you sit back down, he'll shout at you then. He won't like that. Once he is on the move to go to the next position, he doesn't like to be stopped he just likes to keep going. That's what I am saying; you've got to be quite clear with the routine for Barry.*

However, according to Pearson *et al* (2005), routinisation is often accompanied by an obsession with physical care and may be rooted in medical model thinking. Furthermore, the biomedical model;

*'has led to an emphasis on the technical, medically related aspects of the nursing role and to a resulting devaluation of acts related to how individuals experience their own illnesses or disabilities, such as listening, comforting or offering choices. It also creates confusion and dissatisfaction about nursing roles...' (Pearson et al, 2005, p52)*



Therefore, some routines are thought to bring rigidity to the organisation, burnout among staff, and emptiness in residents' lives. They can lead to a system where people are handled as objects on a *'well-greased care factory'* (DeWaele and Van Hove, 2005 p630). These routines may be carried out in the manner described by Alasuutari (2004, p160);

*'We do not know why we follow the routines in our practices because we learned most of them through practice, without anyone explicitly putting into words how things are done and why'* (Alasuutari, 2004, p160).

The use of routines therefore appears to be problematic when an individual follows them without thinking about an individual's needs. This highlights an advantage of making a distinction between routines and rituals, because routine can be defined as;

*'a concept pertaining to strategically designed behavioural patterns (conscious and subconscious) used to organise and coordinate activities along different axes of time, duration, social and physical contexts, sequence and order'* (Zisberg et al, 2007, p452).

Whereas;

*'Ritual action implies carrying out a task without thinking it through in a problem-solving logical way.'* (Walsh and Ford, 1989a, p26)

In the present study, the theme 'following rituals and rushing', and some themes in the category 'doing' indicated that certain routines, such as the daily morning bath and leaving service users naked, may have become ritualised. This is because it appeared that they were being carried out without consideration for an individual's needs or for making their subjective experience of intimate care a positive one. In relation to the morning bath, Walsh and Ford (1989b) have questioned whether the morning is the most appropriate time for bathing to be carried out in care settings. This has been

questioned because mornings tend to be the busiest time for staff, and because some people may prefer to have a relaxing bath last thing before they go to bed (Walsh and Ford, 1989b).

The findings made in this present study have corroborated those made by Melia (1987), who has described how routines were used on a ward for the purpose of 'getting the work done'. Melia (1987) also found that student nurses got along in a ward setting, by learning that 'talking isn't working' and 'looking busy'. Similarly, this thesis, has argued that high value was attached to visible task completion by the staff in this study. This replicates the findings made in a number of studies on nursing care and social care in which 'physical care' has been regarded as 'real care', and the creation of human relationships has not been seen as central to the purpose of care (Oswin, 1978; Smith, 1992; Pearson *et al*, 2005). This attitude is illustrated by a comment made by staff member in an institutional setting for people with intellectual disabilities;

*'Make a bed and you get praised. Interact socially with a patient and you get accused of loafing'* (Ryan and Thomas, 1992, p56).

It can be concluded that staff in the present study perceived the priority to be to attend to physical aspects of intimate care, which had tangible outcomes, and this may have led them to neglect the importance of inter-personal interaction and the emotional and psychological experience of care. Attending to physical aspects of care at the expense of less visible aspects of care, may also have led to staff adopting practices which compromised dignity and were dehumanising.

## **9.12 Conclusion: Part two**

The category 'meaning of intimate care' has offered an explanation for how, despite generally being regarded as 'fully human', staff may have temporarily denied service users' humanness in order to carry out intimate care in

accordance with their understanding of the priorities of the organisation they were working for. In summary, it appears that in this study, the actions of staff were determined partly by their perception of the purpose of intimate care and what their performance would be judged on.

### **9.13 Summary and conclusion**

In this chapter, part one has described the ontology of dignity and shown that maintaining dignity is important for ensuring that service users have a positive experience of intimate care. The effects of failing to treat a person with dignity can be devastating on an immediate emotional and experiential level, and also on reducing self-esteem on a more enduring basis. The chapter has also argued that dignity is a right for everyone, and therefore even if it is not accepted that people with severe and profound intellectual disabilities experience loss of dignity in the same way as the majority of others are likely to, it is important to treat them with dignity regardless.

In the light of the importance of dignity and the findings that the actions of staff did not always maintain dignity, part two of this chapter has developed theoretical ideas to explain why this may have been the case. It has been concluded that for staff to treat a service user with dignity they must see them as 'fully human' and that the organisation they are working for must convey the message that physical care must not be prioritised to the cost of dignity in the provision of intimate care. This chapter has provided a solid foundation for making recommendations for practice and policy. The implications of the study will be discussed in the next chapter following a summary of the conclusions and an evaluation of the strengths and limitations of this study.

## **Chapter 10: Conclusions, strengths and limitations and implications for practice, policy and further research**

*'If intimate care is carried out in a task oriented way, and with a lack of dignity, this could lead to a care-receiver being clean on the outside, but feeling dirty on the inside' (Clark, 2008a).*

### **10.0 Introduction**

It has been argued that research on health and social care has little value unless used to improve care (LoBiondo-Wood and Haber, 1998). This final chapter therefore completes this thesis by drawing out conclusions from the findings presented in earlier chapters and discussing their implications for practice, policy and future research. For the conclusions made to have meaningful implications they must be based on findings that are both valid and reliable, and ideally be generalisable to wider settings outside those in which data was collected (LoBiondo-Wood and Haber, 1998; Morse *et al*, 2002). Therefore this chapter includes an evaluation of the strengths and limitations of this study and discusses the validity, reliability and generalisability of the findings. It is argued that this research used a systematic and rigorous methodological approach, and therefore that the conclusions of this thesis have important implications for practice, policy and research, which will be discussed in the second part of the chapter.

### **10.1 Conclusions**

This thesis set out to explore intimate care in the lives of people with severe and profound intellectual disabilities, and to come to some understanding as to how it is experienced from the perspective of a person with a severe and profound intellectual disability. The research aims were exploratory, because as the review of the literature in chapter 2 showed, very little was known about this area

of care. Chapter 2 also argued that the more general literature about intimate care has indicated that interaction is key to understanding how it might be experienced, and therefore that the experience of receiving care cannot be separated from the provision of that care. This suggested that the experience of care could be studied within a theoretical framework of symbolic interactionism.

Returning to a question posed in the initial stages of the inquiry;

*How does the symbolism that is attached to the way that intimate care is carried out affect the way that it is experienced?*

It is now possible to state that the symbolism attached to the way intimate care is delivered might be understood as dignified or undignified, and that this can have a positive or negative effect on the self-esteem and self-concept of a person with severe and profound intellectual disabilities.

This thesis has explained the central importance of dignity in the experience of intimate care. The relevance of dignity is clearly supported by extant literature which has reported on the experiences of other groups, such as the elderly and hospital in-patients, who have been in receipt of intimate care (for example; Johnson, 1990; Walsh and Kowanko, 2002; Widäng and Fridlund, 2003; Price, 2004; Duffin, 2007). As explained in section 7.1 of chapter 7, the definition of dignity that has been developed for this thesis is;

*Dignity is about feeling and / or being treated and regarded as important and valuable in relation to others. It is a subjective, multi-dimensional concept, but also has shared meaning among humanity.*

Because loss of dignity can affect self-esteem and the self-concept in an adverse manner, it was important to understand why, at times, staff carried out intimate care in an undignified way.

This study has found that recognition of a person's humanity is fundamental to respect for dignity, and therefore in order to treat someone with dignity, a person must first be viewed as 'fully human'. Similarly, Haddock (1996) has concluded that the maintenance of human dignity evolves from the recognition of shared, but unique humanness. One of the most significant findings to emerge from this research was that, when staff approached intimate care as a physical care task, there was a risk that they 'objectified' a service user and interacted in a manner that demeaned and dehumanised them.

Therefore, the findings made from this present study have suggested that for staff to interact with people in ways that humanise and promote dignity, they need to understand that when delivering intimate care, it is not only what they do, but also how they do it, that is important. When I have presented this conclusion to colleagues and professionals, some have commented that *'the staff just don't care'*. I disagree with this. I think that the majority of people entering social care do care about the people they are supporting, but that something happens when they enter the organisations within which they are working that makes their focus shift from 'caring', to carrying out a job in which their performance is judged based on the visible outcome of their action.

Dehumanising actions of staff may therefore not have arisen from malevolence or the attitudes of staff *per se*, but rather been mediated through staff's perceived expectations of the organisation they were employed by, and the colleagues they were working with. There appeared to be a pressure on staff to attend to tasks and activities that had visible and tangible outcomes and these were prioritised over invisible outcomes that might have involved the psychological and emotional experience of the service users. In a similar vein, Becker et al (1961) and Melia (1987) have described how student medics and nurses were socialised into their professional roles, and how they learnt, from qualified staff to carry out 'care' in a routine, rather than individualised, manner. Haddock (1996) has also found that

nurses acknowledged the humanity of their patients, but the focus of health care organisations on processes, outcomes and effective management, could direct their attention away from the fact that patients are human. Arguably, the same may apply in social care organisations.

To summarise, it is concluded that:

- It is important that intimate care is carried out in a way that promotes dignity
- In order for this to happen, care-receivers must be seen as fully human
- Care-givers must understand what dignity means and what needs to be done to maintain dignity
- To maintain dignity, care-givers must not prioritise activities that have visible outcomes at the cost of the subjective experience of care
- In order to carry out intimate care in a dignified manner staff must have the necessary skills
- Sufficient resources need to be available to provide intimate care within an environment that is conducive to promoting dignity and staff need to have enough time to carry out intimate care on a one to one basis without a need to rush

Perhaps the finding that dignity is central to a positive experience of intimate care may appear to be quite obvious, but then why can this aspect of care be neglected? This research has provided an explanation which can answer this question and also make predictions for how dignity in care can be improved. Whilst it is assumed that everyone knows what dignity means and that they strive to promote it in practice and policy, this research has shown that we cannot be complacent. The conclusions made in this thesis have clear implications for practice and policy, as well as for the level at which intervention may need to be focused. However, the utility of these conclusions rests on the credibility of the research findings. And because of this it is essential, before drawing out any

implications for practice, policy and research, to discuss the strengths and limitations of this study.

## 10.2 Strengths and limitations of this study

A particular strength of this thesis is that the research methods were appropriate to the research question and the aims of the study, and the methods and theoretical framework were underpinned by shared philosophical assumptions. Consistency between the aims of the study, methods and the underlying philosophy has been referred to as '*methodological coherence*', and it has been suggested that the rigor and credibility of a qualitative study depends on there being such coherence (Proctor, 1998; Morse *et al*, 2002).

Another strength of this thesis was the systematic use of the method of 'constant comparison', and the congruence between data analysis and the overall research design. Data analysis was inductive and sought to develop findings that were faithful to the social settings being studied, rather than to prove or test a predetermined theory. This means that the representation produced in this thesis was as close to reality as it was possible to get, and that the imposition of preconceived ideas and meaning was minimised.

In section 6.8 of chapter 6, the importance of validity and reliability for establishing the rigour, and therefore the credibility, of this study was discussed. In this thesis it has been acknowledged that there were threats to the credibility of the study, and many of these have been dealt with and counterbalanced using the techniques that were described in section 6.8 of chapter 6, which included triangulation, reflexivity and keeping an audit trail.

Despite the systematic use of these techniques, there remain characteristics of the way in which this research was carried out that might provide grounds for disputing its credibility. The remainder of this section endeavors to anticipate the



ways in which this research might be criticised, discuss how these potential problems might threaten its credibility and, where applicable and appropriate, attempt to challenge and perhaps even negate them. The major criticisms that have been considered to warrant further discussion are; the distortion that arises when participants change their behaviour because they are being observed (reactivity), the absence of first person accounts from participants with severe and profound intellectual disabilities, and the weaknesses and limitations associated with the use of symbolic interactionism as a theoretical framework. Each of these threats will be discussed in turn.

### **10.2.1 Reactivity: 'The Hawthorne Effect'**

Although the effect of the research on the researched is inherent in many studies, including those carried out within the quantitative tradition, a greater expectation is placed on qualitative researchers to defend the validity of their findings by addressing this issue (Robson, 2002).

Ethnographic studies have been regarded as having strong validity because they enable the researcher to observe people acting in their natural environment (Hammersley and Atkinson, 1985). However, as previously discussed in chapter 4, section 4.4, the validity of such studies has also been disputed on the grounds that the presence of the researcher influences the actions of those being studied (Hammersley and Atkinson, 1995; LoBiondo-Wood and Haber, 1998).

Section 4.4 of chapter 4 has also described how these effects can be overcome if the researcher spends long enough in the research setting for participants to become so accustomed to the researcher's presence that they behave as normal. But, whether reactivity can be completely eliminated in participant observation studies is questionable (Robson, 2002). However, Hammersley and Atkinson (1995) have argued that reactivity does not render findings invalid

because the effect of the researcher can be minimised and that monitoring how people respond to the researcher can also be informative.

In this thesis it has been accepted that my presence would have affected the behaviour of participants, and therefore it was important to understand precisely what effect this had. I attempted to develop such an understanding by adopting a reflexive approach and, during data collection, by including my own involvement in the events that I recorded. Data that referred to events I had an obvious impact on, were assigned a specific code and treated as an integral part of data analysis. This enabled me to consider what impact my being there may have had on events, and whether things may have been different had I not been present.

It seems reasonable to assume that one effect I may have had would have been to make staff want to behave in a way that showed themselves in a positive light. It seems unlikely that my presence would have caused staff to interact with service users in ways which they thought would have led to a loss of dignity, and much more likely that they would have wanted to demonstrate, what they thought was good or at least acceptable practice. It is therefore possible that if I had not been present, staff actions and interactions, would have been even less dignified than my data suggested. It is also possible that some of what I have interpreted to be undignified practice was thought by these staff to be acceptable. The idea that staff were not aware that some of their actions were demeaning is supported by interview data, which showed that staff did recognise the importance of dignity as this excerpt from an interview illustrates;

*Sally: Well I think we all respect privacy. I think that we tend to, we've got quite good, I hope we've got high standards here.*

Furthermore, arguably reactivity has not been a threat to the credibility of the findings because my presence was a stable factor throughout observations. The

way that intimate care was carried out varied, despite my being there remaining constant. Whilst I was present there were times when dignity was maintained, but also times when it was not.

Therefore, arguably reactivity has not posed a threat to the validity of the findings because there was variation in the extent to which dignity was maintained. The likely impact of reactivity, actually appears to give support to a conclusion made in this thesis because staff would have acted in a way that they thought demonstrated their 'best practice', and therefore would not have intended to treat service users with a lack of dignity. This means that there must have been something else, other than staff's attitudes towards the people they were providing care for, to explain the loss of dignity. In this thesis, the data were interpreted in such a manner that led to the conclusion that loss of dignity could be explained by staff carrying out intimate care in a task oriented way, which resulted in them temporarily failing to see the care-receivers as being fully human.

This discussion has highlighted that findings from participant observation studies can be highly credible because, as discussed in section 6.8.7 of chapter 6, with this method it is possible to uncover behaviour, social processes, attitudes and beliefs of which participants are not aware, and therefore cannot talk about during an interview. Interviews alone would have given a distorted view of the way that intimate care was carried out, because staff reported that they did maintain dignity, but this was not always corroborated by observation data.

It is also possible that the formality and artificiality of the interview setting may have given rise to unreliable responses from interviewees. Interview accounts are socially constructed and some of the disadvantages of this method are that interviewees may say what they think the interviewer wants to hear, they may have a tendency to talk more about their more socially desirable behaviours, and

they may not have had the opportunity to reflect on the topics that they are asked to talk about (Silverman, 2001; Morse, 2001).

One of the purposes of triangulation of methods was to counteract this problem by collecting data in naturally occurring settings. I also found that the data I collected by asking questions during periods of participant observation allowed me to elicit 'more natural' responses from staff. In the second research setting, I therefore decided that it was not necessary to conduct informal interviews because I was able to elicit the information that I required by asking questions during periods of participant observation. Furthermore, staff often made spontaneous comments to me which I recorded and assigned a code to so that they could be included in data analysis

These comments may have indicated what staff wanted to draw my attention to, or what they thought was important for my research. Often the comments they made were to explain or justify their actions, and were more often related to physical aspects of care rather than the invisible aspects of care such as the subjective experience. For example, when a member of staff left a service user in the bathroom with no clothes on, her comment to me suggested that her concern was primarily about the lady's safety, rather than her dignity, as this excerpt from my observation notes reveals;

*Mary has been hoisted so that she is sitting on the edge of the bath, the side of the bath is down and her legs are hanging over the side. Mary is naked. The bath is yet to be filled up. Lorraine is about to leave the bathroom and says to me; "Mary is normally safe sat like that".*

Spontaneous comments, like the one above added support to my interpretation that staff thought their performance was judged according to the visible outcome of their activity. Some staff also appeared to want me to think that a service user

liked them or was happy with what they were doing, as these excerpts from observation notes and an interview transcript illustrate;

*Bella says "She's sticking her tongue out so she's happy".*

*Caroline says "We've got it down to a fine art now. He won't take the box for anyone else".*

*Sally says "Barry has always shown me affection".*

*Sally: I am one of his favourites, I think. And uhm, he actually lets me do it. I am one of the only people who he lets do it.*

This discussion has articulated how important it was to triangulate findings by collecting data using a variety of methods. However, the extent to which findings could be triangulated was limited because it was not possible to interview service user participants, or for them to tell me directly about their experiences in any other way. As discussed in section 1.3 of chapter 1, this posed a challenge for finding a methodological approach that would meet the aims of this study. The problem of failing to obtain first person accounts will be returned to in the following section in relation to the specific interpretations and conclusions that have been made throughout this thesis.

### **10.2.2 The absence of first person accounts**

This research has sought to understand the experience of intimate care from a care-receiver's perspective. In section 2.13 of chapter 2 it has been argued that approaches from ethnography provided the most suitable methods for collecting data to develop such an understanding.

The aim of ethnography is to spend time with, and observe, people in their natural environment in order to understand '*another way of life from a native*

*point of view*' (Spradley, 1980, p3). In this research, the 'natives' included the people with severe and profound intellectual disabilities who lived in the home, and the members of staff who were employed to work there. There was a clear division between these two groups based on their characteristics and the roles they were assigned to as either 'service user' or 'member of staff'. The initial research question asked '*how do people with severe and profound intellectual disabilities experience intimate care?*' Therefore, ideally, in order for me to gain an understanding of the experience of being a care-receiver, I would have participated in the home as a service user, and experienced being on the receiving end of intimate care for myself. However, for pragmatic and ethical reasons this was, quite clearly, not possible, and in order that the gatekeepers would allow me access to the research settings, I needed to adopt a role that was more akin to that of a staff member than a service user.

Adopting this particular stance took me a step further away from gaining an emic perspective of the service user's experience. According to Wolfensberger, ethnographic studies of devalued people fail to establish a valid epistemology because although people engage as researchers, they do so from the top-down and therefore 'do not see' (Wolfensberger, 1989). This thesis has challenged this view by arguing that it is possible to establish a valid epistemology using ethnographic methodology which is underpinned by critical realism. Taking a critical realist approach implied a necessity to be aware of importing perceptions of a non-disabled assumptive world, which Carnaby and Cambridge (2006a) have asserted are coloured by a society that devalues disability and dependency. In a sense, my research was carried out from a 'top-down', and 'outsider's perspective', however, a view has also been taken that insider and outsider research is complementary and therefore both approaches should be used in the context of inquiry (Peters, 1995).

Ethnography provides a suitable methodological approach for developing an understanding of a social setting from an outsider's perspective. This is because

it is about forming relationships, the search for connections across borders, and the construction of shared meaning (Roets and Van Hove, 2003). Furthermore, Goffman (1961, p7) has suggested that to learn about the worlds of others it is sufficient to be in their company, perhaps implying that it is not necessary to take on the full role of the people being studied;

*'A good way to learn about any of these worlds is to submit oneself in the company of the members to the daily round of petty contingencies to which they are subject' (Goffman, 1961, p7).*

Within the theoretical framework that this research has been conducted, it is accepted that humans are able to put their self in the place of another person and imagine how another person may feel in certain circumstances (Mead, 1934). 'Disability' is only one element embedded in the lives of people labeled with a disability and there are many other human characteristics that are common to us all (Roets and Van Hove, 2003). This sense of a common humanity means that we can ask ourselves 'how would I feel', and look at the experiences of those labeled with a disability in the light of all human experience (Brechtin and Walmsley, 1989).

This research provides an interpretation from just one, non-disabled, person's perspective. If another disabled or non-disabled person were to examine intimate care in the same way that I did, they would be likely to do so from a different perspective and therefore make different findings about the same phenomena being studied. However, the ontological position taken in this thesis was that of Hammersley and Atkinson's (1995) critical realism, which accepts that there are multiple realities, but that it is possible to access and understand a shared reality. Arguably, the interpretations made in this thesis are equally as valid as anyone else's, and in a paper on carrying out 'ethnographically-oriented' research into areas the researcher has no direct experience of, it has been argued that;

*'Research carried out into disability by a disabled researcher cannot on the basis of experience alone be seen to be more legitimate than research carried out into disability by a non-disabled researcher'* (Fawcett and Hearn, 2004, p216).

This research has not led me to believe, nor to assert that I know what it is like to be a care-receiver, but this research has given me the privileged opportunity to spend time observing and reflecting on this phenomenon. This has led me to develop a deeper understanding about the nature of the actions and interactions that take place in the very private context of intimate care. The issue will be returned to later in this chapter when the generalisability of this study's findings is examined.

It has been acknowledged throughout this thesis that the findings and conclusions made were based on my personal interpretation of the events that I observed. I have made choices about what to observe and record and which data to focus my analysis on. The choices that I have made were based partly on my own biases and assumptions about what might be important and these were derived from my personal experiences, as well as from sensitivity to the literature and research findings that I had read prior to, and throughout the study. My personal biases were also influenced by the culture from which I am from, and this means that the data have been analysed from a particular western cultural perspective. This is one of the reasons why taking a reflexive approach was so important, and the inclusion of my reflexive account in appendix 2 enables readers to judge for themselves how my biases may have influenced the method that I used and the subsequent findings.

The conclusions that I made rested on a belief that people with severe and profound intellectual disabilities share a common humanity, and also on a conclusion reached in chapter 9, that a loss of dignity is likely to affect people



with severe and profound intellectual disabilities in the same way as it would the vast majority of other people. If these beliefs and assumptions are refuted, then this thesis could also be refuted. The conclusions were also arrived at from the perspective of symbolic interactionism which is underpinned by certain assumptions, and the validity of this present thesis therefore relies on accepting that these assumptions are valid ones. Therefore, an assessment of the theoretical rationale of the study is of relevance when judging the utility of this study (LoBiondo-Wood and Haber, 1998). This leads to an evaluation of symbolic interactionism in the next section of this chapter.

### **10.2.3 An evaluation of symbolic interactionism**

As explained in chapter 2, section 2.14, initial stages of the inquiry indicated that 'interaction' was pertinent to understanding experience from a care-receivers perspective and subsequently symbolic interactionism was adopted as a theoretical framework for this study. This proved to be a useful and productive perspective within which to frame the study and to make theoretical sense of the findings. Although the theory has been well established and well practiced in sociological academia, critics have put forward objections that have cast the usefulness of the theory into doubt (Ritzer, 1996; Cuff *et al*, 1998). The conclusions that have been reached in this thesis must therefore be seen in the light of the weaknesses of symbolic interactionism. For this reason, the four criticisms that have posed the most serious threats to the credibility of the theory will be addressed.

Firstly, symbolic interactionists have been criticised for using qualitative methods with a philosophical commitment to realism to study the social world (Ritzer, 1996). This criticism cannot be applied to this research because, as discussed in section 3.2 of chapter 3, this study has been carried out in line with critical realism. The use of qualitative methods by symbolic interactionists has also been objected to on the basis that these methods fail to produce credible

findings. This issue has been dealt with in section 6.8 of chapter 6, as well as earlier in this chapter, and therefore will not be repeated here except to say that in this thesis a view has been taken that qualitative methods can yield valid and reliable findings, if carried out systematically and with rigour.

Secondly, it has been argued that symbolic interactionism has not been developed into a formal, systematic theory (Ritzer, 1996). Many of the concepts of symbolic interactionism, such as 'I' and 'me' have been thought to be too vague and abstract to be codified and operationalised, and therefore difficult to examine 'scientifically'. In this present study, the concepts that have been studied, such as 'dignity' and 'self-esteem' have been examined and have been clearly defined. However, it has been necessary to draw upon various theoretical perspectives in order to do this. For example, psychological and evolutionary theories have been utilised in discussing the effect of dignity on self-esteem in chapter 9, section 9.1.

Thirdly, symbolic interactionism has been criticised for focusing on the interactional level at the expense of neglecting the role of culture, social structure and macro-sociological issues in giving shape, direction and meaning to social interaction (Cuff *et al*, 1998). However, as discussed in section 9.11 of chapter 9, symbolic interactionism is not necessarily incompatible with macroscopic theories, and Cuff *et al* (1998) have argued that since its inception in the 1960s, symbolic interactionism has been reconstructed to accommodate the influence of social structures and institutions. In this research, the symbolic interactionist perspective that large scale pattern comes from individuals' joint action did not adequately explain the demeaning and dehumanising actions of staff. This was because the findings revealed that staff generally had a positive attitude towards service users, and generally did see them as being 'fully human'. The data analysed suggested that the role of the organisation, as well as perhaps the wider culture, had a mediating affect on the actions of staff which led to a failure to maintain dignity. The category 'resources and skills' highlighted ways in which

organisational factors could have influenced dignity, and was therefore included in analysis and can be found in appendix 25.

Finally, in contrast to the third criticism, symbolic interactionism has been reproved for failing to focus on micro-level psychological processes such as needs, motives, emotions and the unconscious. In order that these important processes were included in developing an understanding of the experience of intimate care, as stated earlier in this section, theoretical perspectives from psychology have been taken into consideration.

In order to draw this section on limitations of the research to a close, it is concluded that there are multiple realities and multiple ways of looking at the world, and symbolic interactionism offers just one 'lens' through which it can be viewed. No single theoretical framework can account for the multiplicity of social processes and human experience, and the value of drawing upon different sources of understanding, and not seeing them as mutually exclusive has been summed up by Alasuutari (2004);

*'Human reality thus consists of parallel regimes of knowledge that form a kaleidoscope whole' (Alasuutari, 2004, p165).*

The conclusions made in this thesis, therefore, do not preclude or exclude the validity of theoretical contributions from different perspectives to the study of intimate care. These would be welcomed as they would add further to our understanding of this phenomenon, as will be discussed later in this chapter.

A purpose of this study, as stated in section 1.0 of the introduction and in my reflexive account in appendix 2, was to make an original and unique contribution to knowledge that would have the potential to lead to improvements in quality of care. The applicability of research for practice and policy relies on the findings being generalisable beyond the settings in which the research findings are

generated, to the wider population (Mays and Pope, 2000). This chapter therefore proceeds to discuss issues related to the 'generalisability' of this study. The view taken here is that a more appropriate criteria is 'fittingness', a term from qualitative research which will be defined later in the following section.

### 10.3 Generalisability and fittingness

Generalisation is an act of reasoning from the observed to the unobserved (Schwandt, 1997). In quantitative research this is achieved through statistical sampling procedures (Silverman, 2001). Ethnographic research and other qualitative methods use small samples, and this research has therefore been criticised for producing 'anecdotal findings' that cannot be generalised across other settings (Silverman, 2001).

However, Mason (1996) has argued that qualitative researchers should not be satisfied with explanations that are idiosyncratic to a particular case and should seek to produce explanations that have wider resonance. Section 6.4 of chapter 6 has shown how this can be achieved by moving between the particular details of the data and the general by conducting data collection and analysis as an iterative cycle.

In quantitative research, this type of generalisability has been described as analytic generalisability (Miles & Huberman, 1994), which refers to applying findings to wider theory on the basis of how selected cases 'fit' with general constructs (Curtis *et al*, 2000, p1002). The aim of analytic generalisability is to uncover fundamental principles and issues that are abstract and deep enough to have broader relevance than the sample studied. What this thesis has achieved therefore, is to illuminate experiences of specific cases, and use these to enhance our understanding of the diversity of human experience. Therefore, it is claimed that data collected in this study have been analysed at a level abstracted

enough from the specific findings as to reveal something fundamental about what is going on in the provision and experience of intimate care.

As discussed in section 6.8 of chapter 6, in qualitative research, generalisability has also been referred to as 'fittingness' (Guba and Lincoln, 1981). A qualitative study has 'fittingness' if the findings fit contexts outside the current research study settings (Guba and Lincoln, 1981). Fittingness can be demonstrated if information is sufficient for a research consumer to determine whether findings are meaningful to other people in similar situations. Fittingness has been defined as;

*'faithfulness to everyday reality of the participants, described in enough detail so that others in the discipline can evaluate the importance for their own practice, research, and theory development' (LoBiondo-Wood and Haber, 1998, p238).*

Therefore, the most useful indicator of a study's credibility might be when those whom the study concerns regard the findings meaningful and applicable in terms of their own experience (Cutcliffe and McKenna, 1998). In a similar vein, according to Alasuutari (2004) a function of the social sciences is to;

*'provide us with reconstructions of our tacit practices which, if they are deemed accurate, 'ring a bell' among those whom the interpretation in question concerns' (Alasuutari, 2004, p160).*

LoBiondo-Wood and Haber (1998) have suggested that if nurses wish to apply the findings of a qualitative study, they must first validate whether those findings are applicable in their own places of work. A potential problem with this, as previously discussed in chapter 6, section 6.8.7 and earlier in this chapter, is that there may be cases when research findings are applicable, but are not recognised, perhaps because they are beyond the level of awareness,

challenging or painful. However, so far the research findings of this thesis have been recognised by colleagues who work in a variety of care settings and this has been evident from the feedback they have given during formal and informal meetings, and also at a national conference (Clark, 2008b).

This thesis is based on a piece of qualitative research, but makes a strong argument that it is an authentic account of intimate care that has credibility and wider applicability. This confidence is founded on the belief that the study has been carried out systematically and with rigour, and that within the constraints of the methodological approach, all necessary steps have been taken to ensure the validity and reliability of the study. Threats to the credibility of the study have not been evaded, but rather have been discussed, and the steps that have been taken to reduce these threats have been articulated in order that others may judge the credibility of the study for themselves and draw their own conclusions.

This study has therefore provided a body of evidence that should contribute to practice and policy at a local level, within each unit where intimate care is delivered, and also to national policy with regard to how people think about intimate care. These implications have the potential to traverse different settings in which intimate care is delivered. These might include residential services for people with milder intellectual disabilities, services for elderly people, hospitals and people's own homes. Regardless of the physical setting, or the service user or patient group involved, the need for intimate care to be conducted with due attention to dignity has equal applicability.

The study may also have implications for other aspects of care provision, as this excerpt from my methodological journal demonstrates;

*7 August 2006*

*It is difficult to separate intimate care out from the rest of service provision.*

*The same issues seem to apply to intimate care as to other areas of*

*service provision, such as feeding and drinking. For example, some observations that have been made, that have not related to intimate care, could be coded using the same codes as those developed for intimate care.*

This chapter moves on to discuss what the specific implications of this research might be for practice and policy.

### **10.4 Implications for practice**

This research has highlighted that carrying out intimate care in certain ways can be perceived as undignified, and that this can have devastating consequences. It is therefore important that intimate care is delivered in a way that promotes dignity, and this research has implications for how this might be achieved. Some recommendations for practice are presented in figure 10.1, and may have been apparent upon reading the findings in chapter 7. These include the need for doors to be kept shut during intimate care, the need for service users to be covered up wherever possible, and consideration for speaking about intimate care in a dignified manner and in private.

**Figure 10.1: Recommendations for practice**

- Keep service users covered up whenever possible. This may include whilst; waiting for the bath to fill, getting in and out of the bath and sitting on the toilet.
- Avoid the need to enter a room whilst other staff are carrying out intimate care. If it is unavoidable, wait for permission to enter after knocking. Make sure that in rooms where intimate care is provided equipment and items that other people may need to access are not stored.
- Consider developing a system that prevents other service users and staff from entering a room during intimate care. For example, catches on the door that stop the door being pushed open easily, but can be opened in the event of an emergency may help to maintain privacy.
- Assign a time when intimate issues such as continence care can be discussed with other staff in private to avoid these private matters being spoken about in front of other people. An appropriate time might be at staff handover, which could be held in the privacy of an office. If it is necessary to speak about these issues in 'public' areas of the home, be sensitive about the type of language used and the tone and volume of voice.
- Avoid drawing attention to an individual's incontinence, and refrain from speaking about it unnecessarily or in earshot of people who do not need to know.
- Support service users to wear clothing that is easy to take off and put on and therefore promotes their independence.
- Allow time for service users to use the toilet to urinate and defecate in private.
- Provide seating in the bathroom so that service users do not have to sit on the toilet to be shaved or have their teeth cleaned.
- Adhere to any toileting guidelines that are in place and respond promptly to incidences of incontinence.



- Consider developing systems to enable service users to take control over their intimate care. A service user who is non-verbal may be able to ring a bell or press a buzzer next to their bed to alert staff when they have woken up and are in need of assistance.
- Allow service users to make choices as much as possible, and be aware that non-verbal behaviour may be meaningful communication and be indicative of preferences and wishes.
- Allow service users time in private if they indicate that they would like to masturbate.
- Consider the impact of the use of terms of endearment, such as dear, love and darling and how appropriate they are for each individual.
- Be aware that calling service users names, such as 'spotty devil', even if said in jest, could be interpreted as undignified.
- Develop person-centred, individual guidelines which balance the requirements for intimate care to be conducted safely with the needs for thorough hygiene and a positive subjective experience.

Figure 10.1 clearly conveys some of things that should be considered to promote dignity in practice. Although assault on dignity in the context of intimate care provision happens at the direct care level, this research has concluded that the cause may not be rooted with the individual who is delivering that care. This is because although staff ultimately carry out actions that either maintain or compromise dignity, their actions are influenced by organisational and social structures. In this thesis, it has been concluded that for staff to conduct intimate care in a way that promotes dignity, organisational and social goals and priorities must allow for, and encourage, this to happen. This chapter therefore moves on to consider the implications of this research for policy.

## **10.5 Implications for policy**

A policy is a deliberate plan that guides decisions and actions towards those that are most likely to achieve a desired outcome. Policies are instituted to bring about a positive benefit, or avoid a negative effect that has been noticed. This research indicates that the implementation of policies promoting dignity in intimate care will bring about positive benefits for those on the receiving end of care, whilst policies that eliminate undignified practices will avoid negative effects

As previously stated, this research has implications for any setting in which intimate care is carried out, and chapter 2, section 2.10 has explained how the provision of intimate care straddles both health and social care settings. The way that social and health care are organised in England, means that a number of organisations have a role to play in governing, setting standards of conduct and practice and delivering intimate care. Dignity can therefore be influenced by policy at different levels and throughout various organisations.

Policies that can influence intimate care may be understood as operating at both a national and local level and these have been referred to as macro-level and micro-levels respectively (Booth, 1995). This research has implications for policy at the micro-level of the organisations and units within which intimate care is delivered, as well as at the macro-level of central Government.

### **10.5.1 Implications for macro-level policy**

This research has relevance to organisations that have a responsibility for improving quality in the provision of care, and these include the Department of Health (DoH), the Healthcare Commission, the Nursing and Midwifery Council (NMC), the National Health Service (NHS), the General Social Care Council, and the Commission for Social Care Inspection (CSCI).

CSCI regulates, inspects and reviews all adult social care services in the public, private and volunteering sectors in England. Residential services are inspected against the Government's National Minimum Standards for Care Homes for Adults 18-65, and reports are made available to the public. For the homes in this study, the most recent reports available to date were conducted in 2007 and showed that Primrose Cottage received a two star rating of 'good', with some recommendations made for improvement in relation to offering choice opportunities for activities and holidays. Fir Tree House received a three star rating of 'excellent', and no recommendations were made for how the service could be improved. However, the findings made in this present study would suggest that there are things that could be done to improve care in both of the services. Arguably, this illustrates a problem with assessing a service based on minimum standards, because this may fall short of promoting excellence in care. The failure of the inspection system to identify areas for improvement may also be a result of the difficulties of relying on evidence collected in a one-off visit and the difficulties monitoring aspects of care that are carried out in private.

In relation to healthcare settings, The Essence of Care (DoH, 2001c) was designed to improve quality and contribute to the introduction of clinical governance within provider organisations. It has outlined benchmarks for fundamental aspects of patient care, of which dignity was a core, and defined dignity simply as 'being worthy of respect'. A recommendation that can be made from this thesis is that for dignity to be translated in practice, it should be clearly and operationally defined. The definition and model of dignity, as well as the examples of both good and poor practice provided in this thesis could be used for this purpose. This issue is also relevant to policies developed within the units where intimate care is carried out, and so will be returned to in the next section when implications for micro-level policy are discussed.

Therefore an implication of this thesis is that standards may need to be raised, and expectations for maintaining dignity made clearer at the national level. In

order for this to happen, the issue of dignity in care must be prioritised at the level of central Government. The findings made in this research add weight to the growing body of evidence which has led to dignity being placed higher on the Government's agenda for health and social care. This has largely been initiated by concerns about dignity in the care of the elderly. For example, the 'Behind Closed Doors Campaign', which is endorsed by Age Concern England, the British Geriatrics Society and the Royal College of Nursing, aims to raise awareness that *'people whatever their age and physical ability, should be able to choose to use the toilet in private in all care settings'* (British Geriatrics Society, 2007, p2).

In April 2008, the results of a poll carried out by the RCN were reported in which 86% of nurses said that dignity should be a higher priority (BBC, 2008). It is reports like this that have highlighted the problems with maintaining dignity in care and put pressure on the Government to address the issue. In response to this report, the Care Services Minister Ivan Lewis said;

*'Nurses, like other NHS professionals, have a duty to treat patients with dignity at all times, however, they also have a right to expect the necessary support and resources to make this possible. Putting respect for dignity at the heart of patient care is now one of the top priorities for the NHS'* (BBC, 2008).

Having stated a commitment to dignity in the NHS, there follows a responsibility to put this commitment into action. The 'Dignity in Care' campaign was launched by the Government in November 2006, and aimed to stimulate debate and create a care system which put dignity at the heart of care. This included the formation of a 'dignity in care champions network' and a 'dignity in care practice guide' (DoH, 2008). This study could contribute to national guidance on dignity by highlighting issues pertinent to practice and providing examples of how dignity could be improved. The findings made in this research, as well as those made

by the RCN indicate that there is still a long way to go for the Dignity in Care campaign to be effective in eradicating undignified practice and therefore that the recommendations made in this chapter for practice and policy are contemporaneously significant.

This thesis supports a recommendation of the White Paper, *Valuing People* that staff working with people with intellectual disabilities need skills and training to carry out their work (DoH, 2001a). There are a number of bodies involved in training the health and social care workforce, and in relation to social care these include 'Skills for Care' and Learning Disability Award Framework (LDAF). The recommendations this thesis makes for practice in relation to dignity have implications for these bodies to consider when designing and delivering training programmes.

However, as chapter 2, section 2.11 has argued, beyond vocational and skills based training, staff supporting people with intimate care are unlikely to have a discipline or wider organisation to draw on (Cambridge and Carnaby, 2006b). A further problem of social care being outside the realms of a profession is that it lacks a professional body to regulate the workforce. This research has indicated that social care work is a skilled role, that also requires a great deal of sensitivity, and that the consequences of poor practice can be devastating to the individuals on the receiving end of care. This might suggest that the status of social care work as un-skilled and 'non-professional' should be challenged. However, until the Government sees fit to address this issue, it largely falls upon employers to ensure that their workforce have the necessary credentials to carry out their role. The implications of this research for training will therefore be returned to in the next section which discusses the recommendations that this research can make for micro-policy.

### 10.5.2 Implications for micro-level policy

The conclusions made in this thesis suggest that the policies relevant to promoting dignity in the provision of intimate care cover areas including; recruitment, training and supervision, as well as the direct delivery of care. Within residential services for people with intellectual disabilities, the responsibility for developing these policies generally lies with the service provider and residential home manager. Therefore, there is an overlap between the implications of this research for policy and practice, because it is the practitioners who are responsible for developing policies, and also because the implementation of policies is carried out within practice.

The conclusions made in this thesis imply that policy documents should outline the promotion of dignity as being important in the delivery of intimate care. This is particularly important in the light of evidence which has suggested that it is common for service providers' mission statements which assert a commitment to dignity to be lost in more tangible clinical and managerial priorities (Shotton and Seedhouse, 1998).

As alluded to earlier in this chapter, this research has recommended that policies should not only highlight the importance of dignity, but also clearly state what is meant by dignity in operational terms, and how dignity can be put into practice. However, as discussed in chapter 9, section 9.3, attempting to define dignity and convert this abstract concept into tangible examples has been difficult (Fenton and Mitchell, 2002). The definition of dignity that has been provided in this thesis, along with the model of dignity, contributes to enabling a clearer understanding of dignity to be conveyed in policies.

The model of dignity, in figure 7.0, chapter 7, illustrates that dignity is a multi-dimensional concept and that because of its subjective nature, what may be dignified to one person may not be to another. This implies that policies should

not be prescriptive about the actions and interactions that maintain or compromise dignity, but rather to make suggestions about aspects of intimate care that need to be thought through. The properties of dignity listed in the model can be used to help guide staff as to what factors to consider, and to develop a range of options for maintaining dignity. Each of these properties should be considered for each recipient of care on an individual basis.

Policies should therefore convey the importance of staff being sensitive to, and assessing individual needs and wishes. There is a risk that policy can stifle best practice and innovation, and also that they can serve to protect staff and agencies at the expense of intuitive 'best practice' (Cambridge, 2006). Policies must allow for some flexibility and should refer to the use of individual guidelines which can be developed through person-centred assessment. This is because whereas policies cannot specify individual needs, individual guidelines can.

With regard to maintaining dignity in the provision of intimate care, this thesis has argued that the way care-givers interact is imperative to ensuring that those on the receiving end of care have a positive experience of intimate care. Therefore if staff do not have the necessary communication and inter-personal interaction skills, there is a risk that they may deliver intimate care in a way that leads to the loss of dignity. It is the staff, on the front line of service provision who are ultimately responsible for putting policy into practice, and in order to ensure that the sentiments of policies are put into practice, staff must be equipped with the necessary skills and support to enable them to do this.

The conclusions that have been reached in this thesis have indicated that there is a need for training in the delivery of intimate care to address the holistic nature of intimate care and include not only how to provide good physical care, but also how to care on an emotional and psychological level. Training should therefore cover the technicalities of physical care, as well as how to communicate and interact with someone whilst providing care. Staff are unlikely to have

experienced being on the receiving end of intimate care on a long term basis, and this may make empathising difficult. Scenarios based on the research findings presented in this thesis could be used to help staff to put themselves in the place of a care-receiver and encourage reflection and empathy. An example of such a scenario can be found in appendix 24.

Although it may be possible to challenge attitudes through training (Tsiantis *et al* 2000), Walmsely (1989) has suggested that it is more difficult to train people to have the right attitudes than it is to train people to change their behaviour. These findings, along with those made in this thesis, have suggested that it is important to try to recruit staff with positive attitudes towards the people they are caring for, but also to attend to these issues as part of staff training.

A recommendation that can be made from the findings of this thesis is that policies should pave the way for issues around the provision of intimate care to be discussed in supervision, performance reviews, staff discussions and staff meetings. In order for staff to understand the value of carrying out, what some regard as a difficult part of their work, in a sensitive way that promotes dignity, staff need to feel that they are sufficiently valued and supported.

This research would also suggest that an essential criterion for measuring staff performance should be their ability to carry out intimate care in a way that maintains dignity. The expectations for staff to carry out care with dignity should be made clear, and this should not be neglected because of pressure to 'get the job done'. In one study, role ambiguity, which involves being unclear about what the role entails, was identified as being an organisational factor that led to high staff stress and low morale, which in turn can lead to poorer quality of service (Hatton *et al*, 1999).

So far, this chapter has argued that the findings presented in this thesis derive from valid and reliable research and therefore that the conclusions reached in



this chapter, and the recommendations for practice and policy, can be made with confidence. This thesis has therefore arrived at some answers to the initial research questions, but has also raised more questions which could be addressed by further research.

## **10.6 Implications for further research**

Further research could be used to confirm and develop the findings made in this study, as well as to develop our understanding of the phenomenon under study. This study has led to the development of a theoretical explanation for the experience and provision of intimate care. However, grounded theory is never complete; it is fluid, interactive and open ended (Charmaz, 2006). In terms of confirming, and perhaps developing, the findings that have been made in this study there are a number of avenues that could be pursued.

### **10.6.1 Enhancement of credibility**

To further enhance credibility, it would be important to examine the processes studied in this research in other settings. This may include studying intimate care in different types of services for people with intellectual disabilities, in services for the elderly, or in hospital settings. Validity and reliability may also be enhanced if the findings are confirmed when different methodological approaches are used to study the same phenomenon (Hammersley and Atkinson, 1995).

Some commentators have taken a view that the credibility of qualitative research can be established by conducting quantitative research (Cutliffe and McKenna, 1999). The conclusions reached in this thesis make it possible to develop hypotheses, which could be tested deductively using quantitative methods. For example, a hypothesis that has been arrived at is that staff are more likely to see service users as less than human, and to treat them with less dignity, when they perceive intimate care as physical care and prioritise tasks that have visible

outcomes. This hypothesis could be tested by comparing the extent to which service users are treated with dignity in different contexts.

Another hypothesis that could be derived from this research is that dignity was dependent on staff having skills in communicating and interacting with service users. This hypothesis could be tested by evaluating the extent to which service users are treated with dignity before and after staff training in communication and interaction. In a similar way, this thesis has produced a definition and model of dignity, and the effectiveness of these for improving dignity in care could be evaluated by comparing practice before and after their introduction into policy and practice.

### **10.6.2 Furthering our understanding**

A number of areas were identified, that within the confines of this research, it was not possible to explore in depth, and that would lend themselves to further research. For example, it has not been possible to address every aspect of intimate care, and of note, menstruation and gender issues have not been dealt with in any detail.

An area that may increase our understanding of the subjective experience of care from an emic perspective involves studying the non-verbal communication of people with severe and profound intellectual disabilities. Gleason (1989) and Goode (1992) have provided examples of how anthropological techniques can be used to study the social interactions of people with severe and profound intellectual disabilities. These studies have arguably demonstrated the possibility of discovering meaningful patterns in their actions and behaviours. However, as discussed in chapter 1, section 1.3, there are challenges with gaining reliable and valid indications of internal subjective experience by assessing non-verbal behaviour. Our understanding of the communication of people with severe and profound intellectual disabilities is an area that is desperately in need of

advancement, and such advancement could open up more possibilities for research.

Another interesting avenue to pursue would be following from the work of Foucault on the 'medical gaze' (1973). Foucault wrote about the often dehumanising way that medical professionals separated the body from the person, and how the power imbalance allowed them to treat the body as an object for manipulation.

The study has also raised questions that remain unanswered about the experience of care at a psycho-physiological level. Such questions about the experience of touch, and how it feels to be left naked whilst waiting for a bath to fill, could be addressed from a theoretical perspective of 'embodiment'. Embodiment is about the subjective experience of having and using a body, and studies carried out from this perspective are about '*culture and experience insofar as these can be understood from the standpoint of bodily-being-in-the-world*' (Csordas, 1999). Both embodiment and the ideas of Foucault may offer fruitful insights into understanding intimate care in the lives of people with severe and profound intellectual disabilities.

## **10.7 This study's original contribution to knowledge**

This is the first study of its kind to study intimate care and people with severe and profound intellectual disabilities. The research has used ethnographic methods of data collection together with the data analysis tools of grounded theory, and offered a theoretical explanation of the experience of intimate care from a symbolic interactionist perspective, as well as a theoretical explanation for the way that certain aspects of intimate care were carried out by paid staff within an organisational setting. From the findings, existing theoretical ideas about dignity has been extended, and a model of dignity has been constructed that has

practical applications. The research has also combined approaches of gaining consent in a unique and original way.

## 10.8 Closing message

Essentially, the message that I would like to convey is that dignity is likely to be maintained if staff understand that intimate care is more than just physical care. I suggest that if intimate care is carried out in a task oriented way, and with a lack of dignity, this could lead to a care-receiver being clean on the outside, but feeling dirty on the inside. I would like to end this thesis with a quote from Sinason (1992) who wrote about her observations at an old people's home;

*'Someone comes in and washes, toilets, feeds and dresses another human being. This is done, on the whole, quickly but carefully. There are others in the ward waiting their turn. Keeping people clean and alive matters too. A couple of hundred years ago they could have been left to fester and die. But without meaningful human contact another kind of death occurs.'* (Sinason, 1992, p207)

## **Appendices**

## Appendix 1

### Glossary of key and controversial terms

#### Intellectual disabilities

Different professions and different groups of people have different perspectives on what it means to be labelled with intellectual disabilities. For example, the view of a medical practitioner might be very different to the view of a parent of a person with intellectual disabilities. These different viewpoints are reflected in the language that is used to label and describe the characteristics of this group of people. The problems that are inherent with labelling groups of people have been well documented, but the PMLD Network (2007) have argued that a value of labelling is that it is useful to talk about specific groups of people who have distinctive needs and common concerns.

History has seen this group labelled and relabelled numerous times, and over the past century, terms such as 'idiocy' and 'mental subnormality' have taken on an offensive tone and ceased to be used in professional and academic circles. Sinason (1992, p39) has commented that;

*'No human group has been forced to change its name so frequently.'*

The term mental retardation, although still used in the USA, has been replaced in the UK by the term 'learning disabilities'. However, it has been argued that this term has associations with the medical model, and has therefore become outdated (Ho, 2004). At the time of writing this thesis, the term 'intellectual disabilities' had begun to be used with more frequency, and there were signs that this would soon become the most widely accepted term in UK academia. 'Intellectual disabilities' has therefore been used throughout this thesis, and without implying any offence or prejudice.

## **Severe and profound intellectual disabilities**

A number of terms have been used to label and describe the group of people who this thesis is about, including; 'the most severely disabled', 'severe learning disabilities and complex needs', 'profound learning disabilities and complex needs', 'profound and multiple learning disabilities', 'severe mental retardation' and 'profound mental retardation'.

According to the International Classification of Disorders (ICD-10), a diagnosis of 'severe intellectual disabilities' applies to people whose IQ score consistently falls in the range between 20 and 34, and 'profound intellectual disabilities' refers to people whose IQ score consistently falls below 20 (WHO, 1992). People with severe and profound intellectual disabilities often have no formal language skills and are reliant on others to meet all of their daily needs (Samuel and Pritchard, 2001). They may require constant support and supervision in all aspects of their lives, including intimate care. Many people with profound intellectual disabilities have additional physical and sensory disabilities and mental health problems (PMLD Network, 2002), and these people have often been referred to as having 'profound and multiple learning disabilities' (PMLD). Participants in this study have been referred to in this thesis as having 'severe and profound intellectual disabilities' and includes people who have been labelled 'PMLD'.

The World Health Organisation (1992) has classified PMLD as referring to people whose IQ, if measurable, would lie below 20. However, no existing standardised tests are available for the valid estimation of intellectual capacity at low levels of functioning (Nakken and Vlaskamp, 2002). Furthermore, definitions based on IQ offer little in the way of describing the characteristics of this group of people they refer to. Therefore, in the UK, the most widely cited definition was provided by Lacey (1998), who described people with profound and multiple learning disabilities as having profound intellectual impairment with additional disabilities, which may include sensory disabilities, physical disabilities, autism, mental illness, challenging or self-injurious behaviour and significant communication difficulties.

## Staff and care-giver

The homes that participated in this study used the terms 'support worker' or 'support staff' to refer to the people who provided intimate care. In this thesis I have used the term 'staff' for the purpose of brevity and have also chosen this term because it avoids certain associations that are connected to the word 'carer'.

Benner and Wrubel (1989 p1) have used 'caring' to mean;

*'that persons, events, projects, and things matter to people'.*

The word 'care' has also been associated with the idea that something matters, with a moral commitment to protecting dignity, a relational expression of human concern, and also denotes a quality of interaction (Kapborg and Betterö, 2003). Rock (1998) has also suggested that;

*'the word 'carer' is beginning to become synonymous with acts of courage and bravery.'*

The people who are paid to provide intimate care have therefore been referred to as 'staff', because this was considered to be a neutral term. Staff was also used instead of 'participants' in order to distinguish them from the service user participants.

The term 'care-giver' has also been used to refer more widely to people who provide intimate care, outside the settings in which this study took place.



## **Service users**

Various terms have been used to refer to people who receive health and social care services including, 'inmate', 'patient', 'case', 'resident', 'guest', 'client' and 'service user'. All of these words have different shades of meaning and carry different connotations. For example, 'resident' defines people by their roles as living in a particular place and 'client' is closely allied to the word 'customer', which suggests that the individual has certain rights. At the time of writing this thesis, the term used most commonly was 'service user' and was used in this thesis, and as with the use of 'intellectual disability', this is done without implying any offence to the people it refers to.

## **Residential group homes**

*'Group homes are generally accepted to be living units of indeterminate size that provide permanent accommodation for smaller groups of people with learning disabilities who require some staffing input according to their needs and abilities.'* (Sinson, 1993 p46)

In this thesis, a residential group home was defined as a place in which at least three people with an intellectual disability lived, and where support was available twenty-four hours a day from paid social care staff. At least one person who lived at the home must have had severe and profound intellectual disabilities, and been dependent on paid staff to meet their intimate care needs.

## **Appendix 2**

### **Reflexive account**

This is a personal and honest account. It outlines my personal and subjective perspectives allowing the reader to see the claims and assertions that have been made in this thesis in this context. This account is an amalgamation of the reflections that I have made throughout this research, and that have been recorded in my personal journal and methodological journal.

#### **General philosophy**

I believe in the equal value of all human beings and that positive discrimination is necessary for people from disadvantaged groups to be granted equality. My concerns relate to quality of life, quality of care, individualised support, self-determination and these are based on the principles of equal rights and justice. I believe that research should have relevance and be accessible in order to work towards goals of inclusion and empowerment. The end goal of research should have a real impact on people's lives.

#### **Personality and research role**

I am not resistant to change and actively seek to develop myself and my professional conduct. I also see development and change in health and social service provision as positive, vital and as an ethical necessity. I like to question practice (my own and others) and as a deep thinker, I naturally adopt a reflective approach. I am a perfectionist and constantly strive for improvement. This can also make me critical, and whilst my criticism is mainly directed to myself, it is something that I must be mindful of when I am working with other people. I therefore try to 'keep a lid' on any potential criticism that could be aimed towards others. I try to think before I speak which means that if I do feel critical about the

way that something has been done, I will usually respond in a diplomatic way. I am aware that I do not always know the reasons why someone may have done something in a way that I do not agree with, and will usually therefore ask them why, rather than jumping to conclusions and criticising. My intention is to always be critical of actions rather than people. In terms of this research, my perfectionism meant that when carrying out observations, I needed to be careful not to make judgements based on my own personal standards, and to ensure that I had a detailed procedure in place for dealing with poor practice. A protocol was necessary to distinguish between bad practice, and practice that simply was not consistent with my own way of doing things.

In all aspects of my life I will take every opportunity to offer positive feedback and compliments when I can. In the context of this research, it was not appropriate to do this because the role of an ethnographic researcher is to be a 'naïve' learner, and to be non-judgemental. However, I was able to offer staff and service users my genuine thanks for participating in the study, and for making me welcome in the homes, and I think this probably helped to build rapport.

### **Personal background and research methodology**

My educational career began in psychology and this academic discipline indoctrinated me into the philosophy of positivism, and the epistemological view that truth can only be established through quantitative methods which strive for objectivity.

Although this research was carried out within the tradition of naturalism, which accepts the existence of multiple realities, initially there was a tendency for me to try to collect 'objective' data. This was noticeable in some of the initial observation notes that I made. During the initial stages of data collection, I wrote down everything that I saw and heard and avoided recording any of my own interpretations or assumptions about what I observed. I believe that this was a

useful approach, because it allowed for the data to drive the direction of the study without too much influence from my personal biases and interests. This approach was also useful because when I tried to take notes without recording everything that I observed, my notes were much less clear and more ambiguous. When I came to type them up, I could not always work out the context or exactly what happened. However, in later stages it was important to develop a more interpretive approach to data collection and analysis, and therefore to include analytical thoughts in the observation notes that were made.

After enrolling onto the MPhil/PhD course, I commenced a post graduate diploma in Research Methods and this gave me the opportunity to study a range of philosophical approaches to research. Learning about the various positions enabled me to see that the naturalistic approach to the study of human experience was more aligned to my own world view than positivism.

I have come straight from doing my nursing degree to do a PhD. This has been quite a big step, and without the experience of having done a BSc in Psychology I would have found it very difficult. I have also had to draw on skills that I have learnt from previous work experiences. The role of assistant psychologist has provided grounding in generic professional skills such as, communication, report writing, working autonomously, time management and networking. This role and my experiences as a student nurse have also given me a knowledge of local services which has been invaluable for locating and gaining access to research settings.

### **Reasons for choosing to study intimate care in the lives of people with severe and profound intellectual disabilities**

Some PhD students enrol onto programmes which stipulate the nature of the research study to be carried out. I had the luxury, as well as the challenge of deciding what area I wanted to study. This research journey therefore started out

with the need to identify an area of study that would meet the requirements of a PhD programme, and also be of interest to me. Having read some background texts on being a PhD student, such as Phillips and Pugh (2000) and digested the university's regulations and requirements I realised that it was important to choose an area of research that I was passionate about and that would hold my interest for the duration of the study, and also that I needed to make an 'original contribution to knowledge' in the field of intellectual disabilities.

### **Reasons for interest in severe and profound intellectual disabilities**

People with severe and profound intellectual disabilities are often neglected by research because they are perceived as too difficult to work with. I tend to opt for the challenging approach and like to feel that I am supporting those who I believe need support the most. It is difficult to understand life from another person's point of view and this difficulty is heightened if a person has communication difficulties. I thought that this research would give me the time and opportunity to try to understand an area of life from a person with severe and profound intellectual disabilities point of view. I enjoy spending time with people who have severe and profound intellectual disabilities. It was important to carry out research that was very original and had clear practical implications that had the potential to make a difference to people's lives.

### **Reasons for interest in intimate care**

Intimate care is an area that I have been concerned about because whilst working in social and health care settings, I have observed practices which I have thought to be poor, and possibly even abusive. I have also noticed that there is a lack of training in this area.

When I first started to work with elderly people, I was given no training in personal care and had to base the way I provided care to others on the way that I

cared for myself. Some of the people that I worked with were able to tell me what they wanted me to do, and how they wanted me to do it, and this made it much easier. These people were also able to tell me if they liked or disliked something, or if they experienced pain or discomfort. Many people with severe and profound intellectual disabilities are not able to do this. I also thought that the lack of training in manual handling put the people I was caring for, as well as myself, at risk of injury.

Service users and myself were also put at risk because of the lack of training provided on vulnerability and abuse. The lack of training that I had received made me vulnerable because I lacked an understanding of how to respond to abusive behaviour in the context of providing intimate care. On one occasion, I was touched inappropriately by an elderly gentleman whilst I was bathing him. I did not do anything about this incident, because I could not believe it had happened and thought that it either must have been my imagination or that I had exaggerated what had happened. In any other context, I would have regarded his behaviour as sexual assault. I was working for an agency at the time and I did not feel that there was anyone I could tell about this. There were no support or supervision structures in place.

Throughout my career in care, which has spanned fifteen years, I have received no training in intimate or personal care with the exception of shadowing other members of staff. As a learning disability student nurse I attended one teaching session, lasting for one hour on how to give a bed bath in a hospital setting. In practice, I have seen co-workers and mentors carry out intimate care in ways that I have thought to be excellent, but also in ways which I have thought have been extremely poor. At times I have thought that intimate care has been rushed, that not enough privacy or opportunity to relax in the bath has been given, that the person's genitals have not been cleaned thoroughly, or that staff have not communicated with the person they are supporting effectively. My perception has, at times been that intimate care has been carried out as a functional task

and one that needed to be completed as quickly as possible. I could never understand why there was a rush in the morning to get everyone up, bathed, dressed and given breakfast just so that they could sit in the living room whilst the staff spent hours cleaning the house! Why could this not be used for quality interaction, sensory experience and pampering?

I think that intimate and personal care is important to most people, and this view is based on my own feelings about intimate care, what other people have told me and what I have read. If I could not carry out my own intimate care in the way that I like to, I would probably find it upsetting. However, the services I have worked in have had limited understanding about the intimate care preferences of people with intellectual disabilities. Having worked in dozens of homes for people with intellectual disabilities, I have been struck by the lack of attention that is paid to intimate and personal care, beyond the use of soap and a flannel. Where individual guidelines have been in place, their contents have often been limited to basic procedures. General guidelines and policies simply stress the importance of keeping doors shut to protect privacy; encouraging independence, encouraging compliance, and ensuring that water does not exceed a certain temperature. In contrast, my own intimate care regime is very detailed and, as most people's, probably quite unique.

My intimate care regime includes, showering at least daily to ensure that I do not smell, to wake me up and to feel fresh, the occasional bath for relaxation and for when I want to use nice oils, lotions and face masks, or when I am feeling very cold. If the bath water is slightly too cold it is not relaxing and I don't really enjoy it. I go to the toilet regularly (I drink a lot of water) and need to open my bowels at particular times of the day. If I do not have access to a toilet where I can do this it can make me anxious and be quite distressing and I can become uncomfortable and irritable. I brush my teeth at least twice a day but usually more and use floss and mouthwash. I hate going out without brushing my teeth first. If I cannot get to a toothbrush, I chew gum. I wash my hair most days and

use products that I like the smell of and that make my hair feel soft. If I don't use nice products and feel that my hair is in good condition, I feel scruffy and this affects my confidence. I apply moisturiser all over every day because I have a tendency to dry skin and if I don't I think my skin looks unsightly and it can feel uncomfortable. I wear deodorant that suits my dry skin, have a face care routine and apply make-up before I go out. I would feel very uncomfortable if I did not have my make-up on at work or out socially. I file the dry skin on my feet weekly and use a medicated foot cream to keep them soft. If I don't do this and dry skin builds up they get very itchy and uncomfortable. I have to use a fragrance free moisturiser for my hands and apply this every time I wash my hands to prevent cracking. Soap makes my skin very dry and so I use aqueous cream instead. I have also been struck by how much soap is used (which is known to dry the skin) and the lack of use of moisturisers used when supporting someone with intellectual disabilities who has a dry skin condition.

### **Methodological journal excerpts**

**18 November 2005**

I have been picking up on poor communication more than good, I need to actively look for and record good communication.

Whilst observing intimate care, it has been easier to hear than to see because of where I have been positioned in the bathroom or bedroom. This means that I have been able to produce a richer description of the language that is used when interacting than the physical interaction. Therefore, it might be difficult to make conclusions about the use of touch.



## **25 November 2005**

I have been keen for staff to see that service users like me and this is probably for a number of reasons;

- It is in my nature to want people to like me (but not at the cost of failing to speaking out about what I believe in).
- I believe in the value of human relationships and kindness and it also makes me feel good about myself.
- I am aware that it is necessary for service users to like me in order that consent by proxy will be given and implied assent will be assessed positively.

I am also keen for staff to like me and this is partly because I want them to allow me to do the research.

## **9 December 2005**

Staff can be distracted by my presence. They talk to me and at times look at me whilst either chatting to me or giving me an explanation. Sometimes staff tell me about something that happened within the context of care on a day when I was not observing – they want me to know something.

Should I keep quiet whilst observing intimate care so that I don't attract attention away from the service user? The dilemma is that I might need to talk in order to develop rapport and for everyone to feel comfortable. I decided to speak when spoken to.

**10 January 2006**

*My effect of staff's behaviour*

Perhaps staff wash service users more thoroughly because I am there.

Perhaps staff start the morning routine earlier than if I was not there.

Some staff might avoid supporting the service users who are participating in my study so that they avoid being observed by me.

Staff might follow procedures more closely than usual because I am there.

Staff might stand in a certain position so that I can or cannot observe what is happening.

Staff might feel embarrassment or anxiety about being observed.

*My effect on service user's behaviour*

I could be an object of interest but at Fir Tree House, the participants do not show any obvious reactions to my presence.

However, reactions from the general population of being observed during intimate care might include: embarrassment, anger, frustration, violation of privacy, indignation and curiosity (about what I am doing). I cannot be sure that service users do not experience these reactions.

**7 June 2006**

When I observe the care it appears to be ok but when I read the notes back I think 'oh my god, that is terrible'.

**4 August 2006**

Whilst I was traveling up to London by train on a Friday night after work to visit a friend, I took the opportunity to read some journal articles that I had printed off that day. Some of these articles were about ethnography, nursing and reflection. This got me thinking about my feelings towards the people at Primrose Cottage. I had previously acknowledged (to myself) that I did not feel very comfortable around one of the service users and was pleased that she would not be one of my participants due to her volatile behaviour and mental health. When I am at the home I always make an effort to speak to her and to be friendly but I would probably avoid spending time with her if possible.

A while ago I had a conversation with Frank who said that he felt he had developed 'bonds' with all of the service users except Mary. Mary is someone who I have felt tends to get neglected because of the severity of her disabilities. She can be left in her chair for periods of time and does not often get moved about or interacted with (not as much as some of the other service users anyway). I have found that I have made an extra effort to interact with her, partly because I have felt that she is neglected and partly because Frank had suggested that she might be one of my participants. Since Frank has made this comment I am even keener to develop a relationship with her. Is this to prove a point, i.e. is it a challenge to show that it is possible to develop a relationship with her or is it because I want others to see that she likes me (or for me to see that she likes me!)

**17 August 2006**

I feel uncomfortable carrying out a literature search for 'dehumanisation' because I feel that it is condemnatory to the people who I have been studying. By reading about these issues, I might also find that the way I have worked with people with intellectual disabilities has contributed to, or been a result of dehumanising processes. This suggests that I was not keen to look in this theoretical direction, but that it was the data leading me to this area of explanation.

**12 September 2006**

I have been concerned about writing notes whilst I am observing. I am not sure if this is right. Is it dignified? I have therefore asked staff how they feel and how they think the service users have responded. Staff have reassured me that there is no problem with taking notes.

There is a tension and conflict between the need for benevolence and the methodology of ethnography. Ethnography should not involve judgement but in order for this research to benefit participants it might be necessary to identify areas for improvement and for staff training.

**13 January 2006**

Commenting on the amount of butter a member of staff put on the pancakes for service users who had been told that they needed to lose weight might not have been good for building rapport with her!

**27 September 2006**

At times it has been difficult to prioritise my role as ethnographer above that of being a nurse and concerned human being. For example, when staff have rushed people to eat or drink at dinner (as observed on the 25.09.06), I asked how the member of staff would know when the service user has had enough. The member of staff probably realised that I was questioning her actions. To me, raising this point was more important than developing rapport.

**12 December 2007**

At the beginning of the PhD, I remember talking to people who thought that dignity and respect would be central to the thesis. I did not think that these ideas would be particularly prominent in what I observed and in reflecting on that in hindsight, I now realise why. When I have been involved in services providing intimate care in the past, I have noticed that in practice, the terms dignity and respect are used frequently and held in high esteem. However, they are ill-defined and applied very narrowly. In terms of intimate care, dignity and respect have tended to translate into; keeping doors shut (but not locked), encouraging people to wear dressing gowns when they are in any communal areas of the house (even if they are fully covered in pyjamas and do not want to wear dressing gowns) and that staff should tell service users what they are doing.

In the observations that I have made in this study I have also found some examples that I have interpreted to demonstrate dignity. However, there has also been a failure to respect dignity in many of the examples that I have observed. It is important that I did not consciously aim to look for data that would support theories about dignity. This is because it shows that I was not consciously biased towards looking for data to prove my preconceived ideas, but rather that the theory emerged from the data.

## **Appendix 3**

### **Literature review search terms**

#### **Title searches**

Disability / experience (combined)  
Profound / learning disabil\$ (combined)  
Profound / intellectual disabil\$ (combined)  
Profound / developmental disabil\$ (combined)

#### **Title / keyword searcher**

Title - abuse / keyword - learning disabil\$ (combined)  
Title – abuse / keyword - intellectual disabil  
Title – vulnerability / keyword - learning disabil\$  
Title – vulnerability / keyword - intellectual disabil\$

#### **Keywords searches**

Personal care  
Personal support  
Intimate care  
Bath / bathing  
Wash / washing  
Clean / cleanliness  
Body odour  
Hygiene  
Skin care  
Menstruation  
Continence  
Nursing  
Elderly / Old age  
Disability

Physical disability  
Privacy and dignity  
The body  
Touch  
Sexuality  
Learning disabilities  
Intellectual disabilities  
Staff training  
Quality of care  
Experience  
Symbolic interactionism  
Dehumanisation  
Humanness  
Carer experience  
Staff experience  
Dignity  
Self-esteem

**Author searches**

Paul Cambridge  
Steven Carnaby  
Wolf Wolfensberger  
Jocelyn Lawler  
Herbert Blumer  
• Julia Twigg

This list of search terms is not exhaustive. Whilst conducting the literature review, initial findings opened up avenues for further inquiry.

**Key**

\$ = truncation and is used to retrieve all possible suffix variations of a root word

## **Appendix 4**

### **Profiles of the residential group homes**

#### **Fir Tree House**

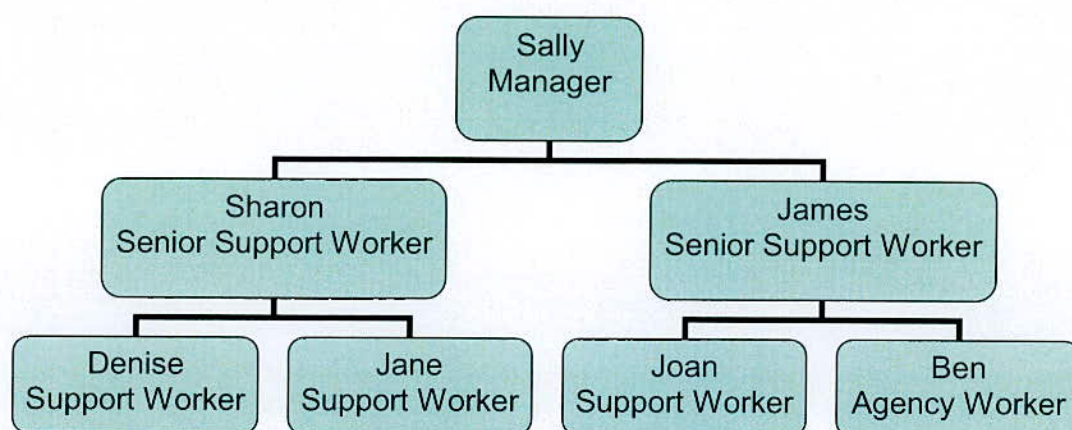
Fir Tree House is a residential home run by a large independent social care provider that, in 2007 had homes in 99 locations across the UK. Fir Tree House is a home to five men who could all be described as having severe or profound intellectual disabilities, some of whom also have physical disabilities and or complex health needs. Four of the men are non- verbal.

The home is situated on a busy road in a small town. There are five bedrooms, four on the ground floor and one upstairs in a loft conversion. Three of the bedrooms have en-suite bath or shower rooms with toilets. There is one shared bathroom with a toilet. The home has a large living room and kitchen diner which leads out into a well maintained garden.

Fir Tree House is managed by Sally who has a number of years experience working in front line intellectual disability services and has managed this home for approximately three years. This was her first managerial position and at the time of the research she was studying for an NVQ management qualification. She was a support worker at Fir Tree House before becoming manager.

Fir Tree House employ 2 senior support workers and 3 support workers (see figure A.1). Members of staff vary in age and the amount of experience they have in intellectual disability services. The period of time that they had worked at Fir Tree House ranged from one to over ten years. Agency staff are employed to cover staff absence.



**Figure A.1: Fir Tree House staff organisational chart**

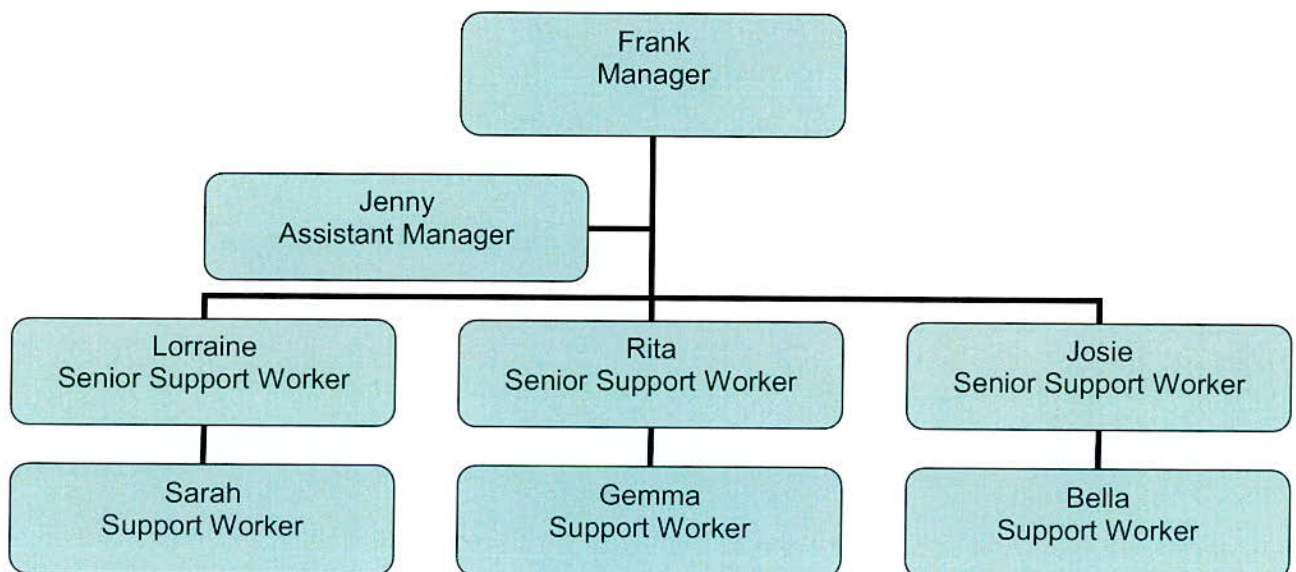
## Primrose Cottage

Primrose Cottage is a residential home for three men and five women, all of whom have moderate to profound intellectual disabilities. All but three are non-verbal, and two could be described as presenting with challenging behaviour. Some of the service users have physical and sensory disabilities or mental health problems. One of the ladies is a wheelchair user. The residents' ages range from late twenties to early sixties. The home is run by social services.

The home is situated in a cul-de-sac which is in walking distance to the local town centre. Primrose Cottage is a large bungalow. All service users have their own bedrooms but none have en-suite facilities. There are two bathrooms, one of which is equipped with a hoist and a bath that is accessible to the lady who uses a wheelchair and is immobile from the waist down. The home has a living room, kitchen and separate dining room. There is a wheelchair accessible garden with seating areas and raised flower beds.

Primrose Cottage is managed by Frank, who has worked in this position for over fourteen years. The staff who participated in this study also included an assistant manager, three senior support workers and three support workers (see figure A.2). There were other agency support workers and a member of administrative staff who did not participate in this study.

**Figure A.2: Primrose Cottage staff organisational chart**



## Appendix 5



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### INFORMATION SHEET FOR SERVICE PROVIDERS

#### **1) What is the purpose of the research?**

The research is part of a PhD being undertaken by Julie Clark who as well as being a PhD student is also a registered nurse, learning disabilities. The research is being supervised by Professor Bob Gates, Head of Subject, Learning Disabilities. The research aims to explore the questions 'how do adults with profound intellectual disabilities experience intimate care?' and 'how is intimate care carried out for adults with severe and profound intellectual disabilities by paid carers in a group home?'

#### **2) How will the research take place?**

The researcher would like to spend some time at your service observing and participating in daily routines, including intimate care. The researcher will join the home in the guise of a supernumerary member of staff. The researcher will not require payment. Duties and shift hours will be agreed with the service managers but must cover periods when intimate care will be carried out. The researcher's role will primarily be to observe the interactions between staff and service users. However, the researcher may participate in tasks as appropriate and as agreed with the service manager.

The researcher is a registered nurse (RNLD) and must therefore adhere to the rules, regulations and guidelines that apply to registered nurses.

#### **3) Why is your service being asked to participate?**

You have been asked to participate because your service is involved in providing intimate care to people with severe and profound intellectual disabilities. The researcher is interested in experiences of providing and receiving intimate care and in staff opinions about giving care.

#### **4) What are the ethical considerations?**

In order to adhere to ethical guidelines for good practice;

- All participants will be fully informed about the nature of the researcher's role.
- Permission to look at or take copies of documents will be sought from the organisation and service manager.
- Anonymity will be assured and protected for all participants. This means that neither the names of the participants or the identities of the homes in which they live or work will be traceable by anyone other than the researcher and her supervisor. The only time this would not apply would be in the event of the researcher suspecting an illegal activity.
- The researcher will pay close attention to issues of informed consent.

#### **5) How will the issue of informed consent be approached?**

'Informed consent' means that potential participants must be given sufficient information about the research in order to make a 'reasoned judgement' about whether to participate (RCN, 1998). This will be dealt with in different ways to meet the needs of three different groups of participants.

##### a) Service users with profound intellectual disabilities

This piece of research aims to understand how adults with severe and profound intellectual disabilities experience intimate care. Due to the severity of the intellectual disabilities, these people are unlikely to be able to make an informed decision about whether or not to participate in the study. The RCN's guidance on research ethics suggested that research should only be carried with people who are unable to give consent if the research cannot be carried out with other adults, or if the research question is specifically associated with the disabilities (RCN, 1998). The aim of this study would be to find out about the experiences of people who require support as a result of their disability and therefore could not be carried out with other adults. According to the Department of Health (DoH, 2001b) a researcher must be able to justify a decision to involve people who are unable to consent on the basis that it is the person's best interests.

The research that is proposed is non-invasive and every measure will be taken to ensure that participants are not harmed or disadvantaged in any way. Although the research findings may not directly benefit the participants, arguably, over time research could lead to improved services for this group of people as a whole. The purpose of this research is to gain a better understanding of the experiences of people with severe and profound intellectual disabilities in order to improve the services they receive. It can therefore be argued that it is in the best interests of the group as a whole. People with severe and profound intellectual disabilities could be disadvantaged if we are prevented from increasing our understanding their needs through research.

A number of 'good practice' strategies will be used to protect and safeguard the interests of this group. The researcher's conduct will be guided by Beauchamp and Childress' (1994) 'principle-based approach' to health care ethics which involves the principles of beneficence, non-maleficence, respect for autonomy and confidentiality.

The principles of beneficence and non-maleficence suggest that the researcher must try to do good and avoid doing harm. These principles will guide the conduct of the researcher in her role as participant observer throughout the study.

In an attempt to respect the autonomy of the individual, procedures will be put in place to assess the individual's level of compliance throughout the study. This will be based on the knowledge of people who know the person well (including the next of kin or advocate) and assessment of the individual's communication. When necessary, advice will be sought from a speech and language therapist. If it is thought that the individual is unhappy with the researcher's presence the researcher will withdraw.

The principle of justice suggests that the needs of the researcher (i.e. to collect data) should be secondary to the service user's needs for care. For example, the researcher will avoid disrupting normal routines for the sake of collecting data.

#### b) Permanent staff who work at the homes

A verbal explanation of the proposed study and an information sheet will be given to potential participants. Potential participants will be given the opportunity to ask questions.

If members of staff agree to participate in the study they will be required to give written consent. This makes it clear that participants can withdraw from the study at any time.

Consent for participating in interviews will be sought using a similar format. It will be made clear that individuals have a right to refuse to be interviewed even if they have agreed to participate in other aspects of the research.

In accordance with the RCN's guidance (RCN, 1998) and in order to safeguard the interests and well being of all the participants, opportunities will be made for staff to speak to someone if they have any concerns regarding the research or the researcher's conduct.

c) Agency staff employed on an occasional basis by the homes

If agency staff are on duty at times when the researcher is also present, they will be fully informed of the researcher's role. The researcher will ensure that the informed consent is obtained (using the above procedure) before including that member of staff in any data collection procedures.

**6) What will happen to the results of the research?**

The results will be used to enable the researcher to develop a greater understanding of the experiences of giving and receiving intimate care.

The results will be written up as a thesis and submitted. Results may also be published in journals. Neither the names of the service users, staff, home or the organization will be reported. From the published material it will not be possible to tell where the research has been carried out.

**7) Who has approved the research?**

The research will be approved by Thames Valley University's Research Degrees Committee and the Faculty of Health and Human Science Ethics Committee.

For further information about ethics approval please contact Alex Bussey (Research Degrees Committee) or Heather Loveday (Faculty of Health and Human Science Ethics Committee).

For further information about any other aspects of the research please email Julie Clark at [julie.clark@tvu.ac.uk](mailto:julie.clark@tvu.ac.uk) or Bob Gates at [bob.gates@tvu.ac.uk](mailto:bob.gates@tvu.ac.uk)

Thank you for taking the time to read this information.

## Appendix 6

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### INFORMATION SHEET for FRIENDS, RELATIVES and CARERS

Your friend/relative is being invited to take part in a research project about the experiences of giving and receiving intimate care. Before you decide whether it is this person's best interests to take part, it is important for you to understand why the study is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please feel free to ask if there is anything that is not clear or if you would like more information.

#### **1) What is the purpose of the research?**

The research is part of a PhD being undertaken by Julie Clark who as well as being a PhD student is also a registered nurse, learning disabilities. The research is being supervised by Professor Bob Gates, Head of Subject, Learning Disabilities, Thames Valley University. The research aims to explore the questions 'how do adults with profound intellectual disabilities experience intimate care?' and 'how is intimate care carried out for adults with severe and profound intellectual disabilities by paid carers in a group home?'

The researcher would like to spend some time at your friend/relative's home to observe and participate in every day routines.

#### **2) Why has my friend/relative been chosen?**

Your friend or relative has been asked to participate because he/she relies on staff to provide intimate care. The researcher is interested in learning about these experiences from the perspective of your friend/relative.

#### **3) Do I have to agree for my friend/relative to take part?**

You are being asked to decide whether it is in your friend/relative's best interests to take part. According to the Department of Health (DoH, 2001), a researcher must be able to justify a decision to involve people who are unable to consent on the basis that it is the person's best interests. In order to determine what it is in



each person's best interests, consent by proxy will be obtained using a 'circles of support' approach. In addition, participants may be able to indicate implied consent through their non-verbal communication throughout the course of the study.

A circle of support is made up of people who know and care for an individual and who are thought to be in the best position to advocate and make decisions on that person's behalf. A decision on whether it is in the service user's best interests to participate will be made by a circle of support which will include at least one family member (if possible), an advocate (if possible), the service manager and a key worker.

A person will only be included in the research if everyone agrees that it is in their best interests. For example, if a member of the circle believes that an individual shows signs of discomfort when unknown people are present; a decision not to include that person will be made.

As a second indication of best interests, 'implied consent' will be assessed throughout the study. An example of implied consent is when a person holds out their arm to have an injection. The notion of implied consent rests on an assumption that it is possible to interpret facial expressions, vocalisations and behaviours as meaningful communication.

A communication passport will be used as a tool for assessing implied consent. A communication passport contains important information about a person who is unable to speak for themselves in an easily accessible format. The aim of the passport is to enable people who may not know the individual well to interpret their non-verbal communication. The researcher and circle of support will use this information to infer the person's responses to the researcher's presence. For example, if a member of the circle notices that the person shows signs of distress or unhappiness when the researcher is present, the researcher will withdraw. If an individual does not have a communication passport, this will be developed prior to the start of research.

#### **4) What will my friend/relative have to do if they participate in the research?**

The researcher will spend some time getting to know the person by interacting and participating in ordinary daily activities. When the researcher has built a positive relationship with the person, the researcher will join him/her whilst a member of staff provides intimate care. The researcher will not carry out intimate care herself but may act as an assistant to the member of staff.

The researcher may record things that have been observed and said. This will be completely anonymous, your friend's/relative's name will not be recorded. However, in the event of bad practice being observed the researcher has a responsibility to report it to the service manager.



**5) What will happen to the results of the research?**

The results will be used to enable the researcher to develop a greater understanding of the experiences of giving and receiving intimate care.

The results will be written up as a thesis and submitted. They may also be published in journals. Neither your friend/relative's name nor the names of the members of staff who provide care, nor the name of the home will be recorded. There will be no way of tracking who has participated in the research.

**6) Who has approved the research?**

The research has been approved by Thames Valley University's Research Degrees Committee and ethical approval by the Faculty of Health and Human Science Ethics Committee.

For further information please contact either Julie Clark at [julie.clark@tvu.ac.uk](mailto:julie.clark@tvu.ac.uk) or Bob Gates at [bob.gates@tvu.ac.uk](mailto:bob.gates@tvu.ac.uk) or on 01753 697631.

## Appendix 7

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Faculty of Health and Human Sciences**

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### PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research project about the experiences of giving and receiving intimate care. Before you decide whether to take part it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please feel free to ask if there is anything that is not clear or if you would like more information.

#### **1) What is the purpose of the research?**

The research is part of a PhD being undertaken by Julie Clark who as well as being a PhD student is also a registered nurse, learning disabilities. The research is being supervised by Professor Bob Gates, Head of Subject, Learning Disabilities. The research aims to explore the questions 'how do adults with profound intellectual disabilities experience intimate care?' and 'how is intimate care carried out for adults with severe and profound intellectual disabilities by paid carers in a group home?'

The researcher would like to spend some time at your place of work observing and participating in every day routines.

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

You have been asked to participate because you are involved in providing care, possibly including intimate care, to people with severe and profound intellectual disabilities. The researcher is interested in your experiences of providing intimate care and in your opinions about giving and receiving personal care.

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

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

**4) What will I be asked to do if I take part?**

The researcher may ask you if she can join you whilst you provide intimate care.

The researcher may record things that have been observed and said. This will be completely anonymous, your name will not be recorded. However, in the event of bad practice being observed, this cannot be dealt with as a confidential issue and the researcher has a responsibility to report it to the service manager.

At some stage, you might be asked to participate in interviews with the researcher. This will involve an informal discussion which will be tape recorded. You will be asked for your consent for each interview and can refuse at any time and withdraw at any time from any part of the research.

**5) What will happen to the results of the research?**

The results will be used to enable the researcher to develop a greater understanding of the experiences of giving and receiving intimate care.

The results will be written up as a thesis and submitted. They may also be published in journals. Neither your name, the names of the service users or the organization for which you work will be written. The reader will not know who has participated in the research.

**6) Who has approved the research?**

The research has been given approval by Thames Valley University's Research Degrees Committee and ethical approval by the Faculty of Health and Human Science Ethics Committee.

For further information please contact either Julie Clark at [julie.clark@tvu.ac.uk](mailto:julie.clark@tvu.ac.uk) Bob Gates at [bob.gates@tvu.ac.uk](mailto:bob.gates@tvu.ac.uk) or on 01753 697631.

## Appendix 8

TVU  
LONDON

**Thames Valley University  
Faculty of Health and Human Sciences**

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### PARTICIPANT INFORMATION SHEET for INTERVIEWS

You are being invited to take part in a research project about the experiences of giving and receiving intimate care. Before you decide whether to take part it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please feel free to ask if there is anything that is not clear or if you would like more information.

#### **1) What is the purpose of the research?**

The research is part of a PhD being undertaken by Julie Clark who as well as being a PhD student is also a registered nurse, learning disabilities. The research is being supervised by Professor Bob Gates, Head of Subject, Learning Disabilities. The research aims to explore the questions 'how do adults with profound intellectual disabilities experience intimate care?' and 'how is intimate care carried out for adults with severe and profound intellectual disabilities by paid carers in a group home?'

I would like to spend some time asking you some questions about your experiences of providing intimate care.

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

You have been asked to participate because you are involved in providing intimate care, to people with severe and profound intellectual disabilities. The researcher is interested in your experiences of providing intimate care and in your opinions about giving and receiving personal care.

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

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

**4) What will I be asked to do if I take part?**

The interviews will involve informal discussions which will be tape recorded, with your permission. You will be asked for your written consent for the first interview and for your verbal consent for any subsequent interviews. You can refuse to take part at any time and withdraw at any time from the interview.

The tape recordings will be confidential and only the researcher will listen to them. Any notes taken at the time of the interview and the interview transcripts will be anonymous and there will be no way of identifying who has taken part. However, in the event of bad, dangerous or abusive practice being disclosed, this cannot be dealt with as a confidential issue and the researcher has a responsibility to report it to the service manager.

**5) What will happen to the results of the research?**

The results will be used to enable the researcher to develop a greater understanding of the experiences of giving and receiving intimate care.

The results will be written up as a thesis and submitted. They may also be published in journals. Neither your name, the names of the service users or the organization for which you work will be written. The reader will not know who has participated in the research.

**6) Who has approved the research?**

The research has been given approval by Thames Valley University's Research Degrees Committee and ethical approval by the Faculty of Health and Human Science Ethics Committee.

For further information please contact either Julie Clark at [julie.clark@tvu.ac.uk](mailto:julie.clark@tvu.ac.uk) Bob Gates at [bob.gates@tvu.ac.uk](mailto:bob.gates@tvu.ac.uk) or on 01753 697631.

## Appendix 9

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### CONSENT FORM

**Title of Project:** Intimate Care in the Lives of People with Severe and Profound Intellectual Disabilities: An ethnographic study using grounded theory within the theoretical framework of symbolic interactionism

**Name of Researcher:** Julie Clark, Room C11B, Slough

**Name of Supervisor:** Prof Bob Gates, Head of Subject, Learning Disabilities

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I agree to take part in the above study. ☐

Name of participant: .....Signature:.....Date:.....

Researcher: .....Signature:.....Date:.....

## Appendix 10

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Faculty of Health and Human Sciences

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### CONSENT FORM for INTERVIEWS

**Title of Project:** Intimate Care in the Lives of People with Severe and Profound Intellectual Disabilities: An ethnographic study using grounded theory within the theoretical framework of symbolic interactionism

**Name of Researcher:** Julie Clark, Room C11B, Slough

**Name of Supervisor:** Prof Bob Gates, Head of Subject, Learning Disabilities

**Please initial box**

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

☐

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

☐

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

☐

Name of participant: .....Signature:.....Date:.....

Researcher: .....Signature:.....Date:.....

## Appendix 11

### Action plan for gaining access and obtaining consent at Fir Tree House

Action	Notes	Date Completed
Verbal agreement from service manager	The manager expressed how keen she was for the home to be involved in the research.	July 2005
Protection of Vulnerable Adults check	Checked with recruitment department at TVU. If the section 'Protection of Vulnerable Adults list information' of the CRB says 'none recorded' then a POVA should not be necessary.	CRB disclosure form dated Feb 2005  Photocopies sent in July 2005
Approval from area manager and organisation	Received verbally via the service manager.	Letter received from service manager dated Sept 2005
Written agreement from service manager		Letter received from service manager dated Sept 2005
Attendance at a staff meeting to meet staff team	See meeting notes for issues discussed during this meeting.	16 <sup>th</sup> Sept 2005
Staff consent forms and participant information forms distributed	Emailed service manager who distributed forms to staff.	30 <sup>th</sup> Aug 2005
Opportunity provided for potential participants to ask questions	Staff meeting – no questions were asked. An issue was raised by Denise with regard to staff changing their behaviour because they know they are being observed. I reassured Denise that this is a good point but that it is an issue which I will have to address.	16 <sup>th</sup> Sept 2005



	Subsequent visits – questions asked by James about what would happen to the results of my work and whether they would have any practical application. I told the staff that there would be journal articles written and that this might contribute towards prompting services to think about how care could be improved.	20 <sup>th</sup> Sept 2005 6 <sup>th</sup> Oct 2005 12 <sup>th</sup> Oct 2005
Signed consent forms collected	These were left with people over a period of time, so that they had time to think and did not feel pressurised to sign.	Oct 2005
Standards of acceptable and unacceptable practice agreed	Discussed during a meeting with service manager. The service provider has policies that can be used. Documents/legislation to be used as a guide.	Sept 2005
Standards written up and distributed to staff members, researcher supervisor for comments	I have decided that this is not necessary because it states in the Participant Information (see appendices) that confidentiality will be broken if poor practice is observed and the standards that are to be used are those that staff should be following as part of their job description and legal requirements.	Sept 2005
Amendments made to standards	Not applicable	Not applicable
Identify person for staff to speak to if they have concerns	Service manager discussed this with her line manager who agreed to take on the role.	30 <sup>th</sup> Aug 2005
Negotiate hours of researcher's attendance	Discussed during a meeting with the service manager. Hours are to be agreed on a weekly basis (see meeting notes).	30 <sup>th</sup> Aug 2005
Negotiate researcher's duties as a member of the staff team (Morse and Field, 1996)	Discussed during a meeting with the service manager and at a staff meeting.	30 <sup>th</sup> Aug 2005  16 <sup>th</sup> Sept 2005

Identify circle of support for each potential participant	<p>Two of the service users have been identified by the service manager as possible participants.</p> <p>The key worker, manager and another member of staff will form the circle of support.</p>	30 <sup>th</sup> Aug 2005
Distribute information to the circle of support	Staff were provided with an information sheet for friends, family and carers (see appendices). I was not sure if the circle had read these and therefore took another set to the next meeting. Meetings were arranged with the circles for Barry and Simon on the 14th and 18th Oct 2005.	Oct 2005
Provide an opportunity for the circle of support to ask questions	Meeting arranged for the 14 and 18 Oct 2005.	18 <sup>th</sup> Oct 2005
Obtain written 'consent by proxy'	This action point was later amended and it was decided that consent by proxy would be recorded in the minutes the circles of support meetings. This was because written consent is not lawful and is therefore not necessary.	N/A
Ensure all participants have communication passports	All service users have communication passports which have been produced by Sharon. SALT assessments?	Checked on 30 <sup>th</sup> Aug 2005
Plan a schedule for assessing levels of implied consent	This has been agreed at circles of support meetings for each participant. This will be done both informally and formally at staff meetings.	Oct 2005
Researcher to spend time in the setting to get to know staff and service users	5 visits between 25th May and 6 <sup>th</sup> Oct 2005. 30 Aug 2005 (Meeting with service manager), 16 Sept 2005 and 20 Sept and 6 Oct visits.	Oct 2005

Assess the relationship between researcher and service user participants for signs of implied consent	On-going throughout the course of the research.	On-going
Begin observations of intimate care activities	With agreement of the manager Barry and Simon's circles of support and staff participants.	27 <sup>th</sup> Oct 2005

## Appendix 12

### Action plan for gaining access and obtaining consent at Primrose Cottage

Action	Notes	Date Completed
Verbal agreement from service manager	First meeting with the home manager - Frank	Feb 3 2006
Approval from area manager and organisation	Email from Frank	April 27 2006
Written agreement from service manager	Email from Frank	April 27 2006
Discuss with care manager	Phone call to care manager. The care manager is happy for the research to go ahead and has confirmed this by email.	April 28 2006
Provide copy of CRB disclosure		June 2006
Attendance at a staff meeting to meet staff team	Met with staff team and gave a short, informal presentation about my research, disseminated information and gave an opportunity to ask questions.	Feb 8 2006 July 12 2006 (see notes)
Staff consent forms and participant information forms distributed	Frank distributed forms at staff meeting on June 26 2006	June 26 2006
Opportunity provided for potential participants to ask questions	Staff meeting and informal opportunities	July 12 2006
Signed consent forms collected	Collected Mon Aug 7	August 7 2006
Standards of acceptable and unacceptable practice	Can use flow diagram already written up. Discussed with	June 16 2006

agreed	manager. Frank also discussed with staff at meeting. Staff raised issue of confidentiality and reporting to supervisor.	
Identify person for staff to speak to if they have concerns	Care manager	31 July 2006
Agree on hours of researcher's attendance	Discussed at staff meeting	12 July 2006
Agree on researcher's duties as a member of the staff team	Discussed at staff meeting Discussed with Frank	12 July 2006 28 July 2006
Identify circle of support for each potential participant	Circle's identified by senior staff and care manager	18 April 2006
Distribute information to the circle of support	Frank will speak to parents and send copies of forms. Julie will distribute forms to staff and the care manager.	25 April 2006
Provide an opportunity for the circle of support to ask questions	Opportunities given to all members of the circle to meet.	12 July 2006
Obtain verbal 'consent by proxy'	Received by telephone and in face to face meetings.	12 July 2006
Ensure all participants have communication passports	Communication profiles designed and will be distributed by Frank.	23 August 2006
Plan a schedule for assessing levels of implied assent	Implied assent will be assessed as an on-going process and reviewed at staff meetings	23 August 2006
Researcher to spend time in the setting to get to know staff and service users	18 visits June 2006 – August 2007	18 August 2006
Assess the relationship between researcher and service user participants for signs of implied consent	Assessment carried out by the staff team	18 August 2006
Begin observations of intimate care activities	Observations started when all actions were completed	25 August 2006

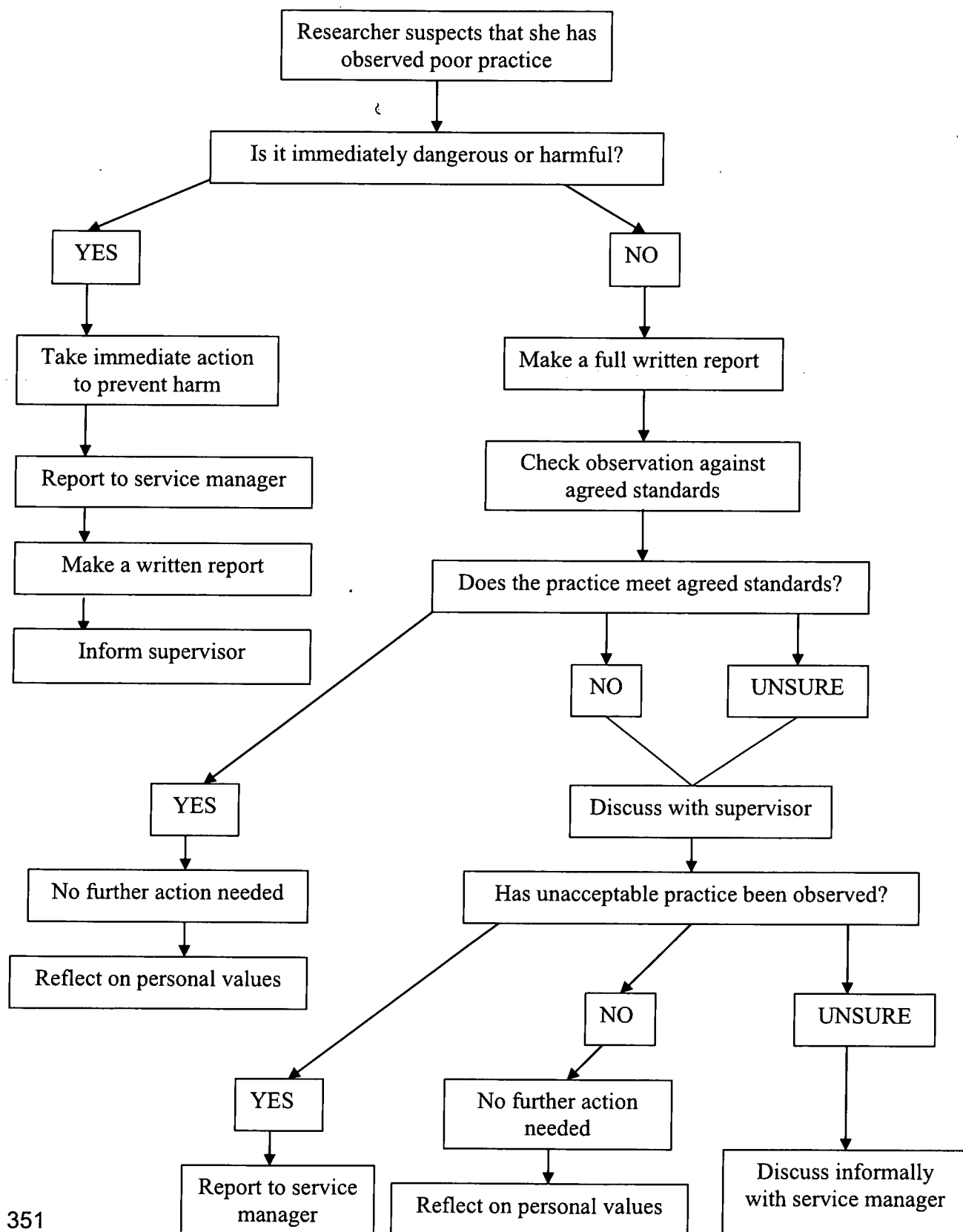
## Appendix 13

### Communication profile (template)

This is how I say yes	
This is how I say no	
This is how I say I am happy	
This is how I say I am sad	
This is how I say I am excited	
This is how I say I am angry	
This is how I say I am scared	
This is how I say I am tired	
This is how I show that I like you	
This is how I show that I don't like you	
This is how I say 'go away'	
This is how I say that I want something	

## Appendix 14

### Action plan for responding to suspicions of poor practice (July 2005)



## **Appendix 15**

### **Responding to suspicions of poor practice:**

#### **Notes to accompany flowchart**

The following documents are to be consulted in the event of the researcher witnessing poor practice.

- Department of Health (2003) Care Homes Regulations: National minimum standards. The Stationary Office: London.
- General Social Care Council (2002) Social Care Workers Code of Practice. General Social Care Council: London.
- Nursing and Midwifery Council (2004) The NMC Code of Professional Conduct: Standards for conduct, performance and ethics. London: NMC.
- Individual service user guidelines
- The service providers, and residential homes' policies and procedures



## Appendix 16: Interview schedules

### Interview schedule 1

Greeting, Explanation (tape recorder), Friendly questions

Throughout interview

- Express cultural ignorance
- Express interest
- Restating (and prompting for what happens next)

Could you describe a typical morning?

Could you describe what you do when you support Barry / Simon?

Can you tell me what happens between the time when you start work in the mornings until the time everyone is ready to start the morning activities?

Can you describe what happens when Barry / Simon has a shave?

Could you describe what you do when you shave Barry / Simon?

After you shave Barry / Simon, what do you do next?

Could you give me an example of...?

Could you tell me about some of the experiences you have had supporting Barry / Simon?

What terms would you use to refer to bathing and showering etc?

If you were talking to Barry / Simon, what would you say?

If you were talking to another member of staff, what would you say?

When you are brushing Barry / Simon's teeth, what do you say?

## Interview schedule 2

These questions include descriptive, structural and contrast questions. They were devised following analysis of the first set of interviews and data collected from observations.

### **Intimate care**

Can you describe the kinds of jobs and tasks that you are paid to do when working here?

What would you call intimate care?

When you are talking to other staff, what do you call intimate care?

What are the differences between intimate care and personal care?

What are all the things that are involved in personal and intimate care?

How do you know what to do when you carry out intimate care?

### **Routines**

In what ways are the weekends different to weekdays?

What are the differences between how intimate care is provided to Barry and Simon?

### **Communication and Service user experience**

What are the ways that you ask Barry / Simon to do something?

What do you do to try to make intimate care nice for Barry / Simon?

What are the things that Barry / Simon like and dislikes about intimate care?

How do you know what Barry / Simon like and dislike?

What kinds of choices to Barry / Simon make?

What kinds of choices do you offer to Barry / Simon?

How do Barry / Simon make the choices?

What are the things that Barry / Simon are asked to do?

## **Appendix 17**

### **Documents included in data analysis**

#### **Fir Tree House**

##### **Policies**

'Bathing – Residential Care'

'Infection control'

##### **Procedures**

'Infection Control'

##### **Daily diaries**

26 March – 6 April (twelve days)

##### **Risk assessments**

Risk assessment for Barry – 'Using the shower'

##### **Support guidelines**

Support guidelines for Barry – 'Aim: To ensure that Barry starts his day with his preferred routine'

##### **Other**

Staff Communication Book - One entry 9 March 2006 related to intimate care

#### **Primrose Cottage**

##### **Policies**

'Cross-Gender Personal Care'

## Appendix 18

### Domain analysis worksheet (Spradley, 1980)

1. Semantic Relationship: \_\_\_\_\_
2. Form: \_\_\_\_\_
3. Example: \_\_\_\_\_

Included Terms	Semantic Relationship	Cover term
_____	_____	
_____	_____	
_____	—————→	
_____	_____	
_____	_____	
_____	_____	
_____	_____	

Included Terms	Semantic Relationship	Cover term
_____	_____	
_____	_____	
_____	—————→	
_____	_____	
_____	_____	
_____	_____	
_____	_____	

## Appendix 19

### Descriptive question matrix (Spradley, 1980)

	SPACE	OBJECT	ACT	ACTIVITY	EVENT	TIME	ACTOR	GOAL	FEELING
SPACE	1								
OBJECT		2							
ACT			3						
ACTIVITY				4					
EVENT					5				
TIME						6			
ACTOR							7		
GOAL								8	
FEELING									9

#### 1 Space - Description of the home

Front door

Hallway

Barry's room on the right with single bed, ensuite shower room and a basin in the bedroom

Simon's room at front of house with single bed and ensuite bathroom

Another service user's room with basin

Office on the left with desk and chair

Bathroom on the right with bath chair, basin and toilet

Another service user's room on the right with a sink

Living room with TV and eight seats (sofas and three single arm chairs)

Kitchen/diner

Garden at rear with slope and seating area

(NB It was not appropriate to produce a diagram of the house because this could have been recognisable and compromised confidentiality)

#### 2 Objects – involved in intimate care

Toilets

Baths

Showers

Shower head

Taps

Basins

Towels

Bath mat

Products

Toothbrush / electric toothbrush

Clothing

#### 3 Acts - involved in intimate care

Communicating  
Interacting  
Carrying out intimate care activities

#### **4 Activities - involved in intimate care**

"Toileting"  
Bathing  
Showering  
Washing ("strip wash")  
Shampooing  
"Padding"  
Dressing  
Changing  
Putting on lotions and creams  
Shaving  
Cleaning teeth

#### **5 Events - that occurred during intimate care**

Incontinence  
Seizure  
Going out

#### **6 Time - periods**

Intimate care  
Breakfast  
Cleaning  
Morning activity  
Tea  
Lunch  
Writing diaries  
Handover period  
Afternoon activity  
Tea  
Cooking  
Dinner  
Clearing up  
Evening activity  
Getting "ready for bed"  
Watching TV

## **7 Actor – the people involved**

Service user  
Support staff  
Senior staff  
Manager  
(Researcher)

## **8 Goals – of intimate care**

Getting service users clean, shaved, teeth brushed and dressed presentably  
Getting the work done in time for breakfast and day services  
Pampering  
Maintaining comfort

## **9 Feelings – involved in relation to intimate care**

Disgust  
Pleasure  
Enjoyment  
Impatience  
Frustration  
Acceptance

## **Appendix 20**

### **Findings from phase one of analysis: description of intimate care**

This description has been developed using Spradley's (1979) approach to domain analysis and involved taking data from the domain analysis worksheets for space, actor, activity, object and act.

The descriptive account provided here describes intimate care in the two group homes. This shows which places, people, activities, objects and acts have been observed, and included in analysis. It is acknowledged that there are other activities, people and places involved in the provision of intimate care, that have not been covered by the data collected in this study.

The people, or 'actors' involved in intimate care were;

- Home manager
- Deputy manager
- Senior support worker
- Support worker
- Service user

All service users had severe or profound intellectual disabilities and communicated using facial expressions, vocalizations and body language. Some had additional physical or sensory disabilities, and one gentleman had a diagnosis of autism.

The places where intimate care was observed (spatial) were;

- En-suite shower room
- En-suite bathroom



- Bedroom
- Shared bathroom

The intimate and personal care activities observed were;

- Getting the bathroom ready
- Bathing
- Showering
- Washing
- Toileting
- Brushing teeth
- Shaving
- Changing pads
- Dressing
- Putting deodorant on
- Putting aftershave or perfume on
- Brushing hair
- Drying hair

The material objects involved in intimate and personal care were;

- Toilet, bath, shower, shower seat, basin, taps, shower head, bath seat, hoist
- Flannel, sponge, body puff, wet wipes, disposable towels, toilet paper
- Products (soap, liquid soap, shower gel, medicinal bath products, toothpaste shaving foam, shaving balm, medicated cream for eczema and dermatitis, aftershave, perfume)
- Toothbrush, electric toothbrush, shampoo, medicated shampoo, razor, electric shaver, comb, brush
- Towel, bathmat, dressing gown

These domains have been used to produce a detailed narrative and descriptive account of intimate care.

### **Descriptive account of how intimate care was provided**

Staff arrived at 7.30am at Fir Tree House and at 7.00am at Primrose Cottage for the 'early shift'. There were two or three members of staff on shift at Fir Tree House and three or four members of staff on shift at Primrose Cottage during the 'early' and 'late' shifts. Sometimes a manager was also present, but he or she did not always get involved in hands on support work. In each home there was a member of staff on night duty, and at Primrose Cottage there was also a member of staff on 'sleep in' duty.

In the morning, when the early shift staff arrived, the night staff gave the early shift staff a brief 'handover', which involved telling them what happened overnight. The night staff left and the early shift staff sometimes made tea and had a chat before sitting down in the living room to allocate work duties. The most senior person on shift was responsible for allocating duties, including who would carry out intimate care for each service user. Staff were usually asked who they want 'to do'. One member of staff was allocated between one and three service users who they were responsible for supporting to get out of bed and get ready for breakfast. Sometimes there was a discussion about what time everyone needed to 'be ready' and which service users therefore needed to get up first. Staff sometimes also decided who would be responsible for household and cleaning tasks and supporting service users with the day's activities. When the meeting was over, staff started work on their allocated duties.

By this time, some service users would have already got out of bed independently, but most were still in bed when staff entered their rooms. Service users were then either taken to their en-suite bathroom or a communal bathroom

to have a bath or shower. All of the service users who participated in this study were given a bath or shower in the morning, every morning.

### **Bathing, showering and washing**

All service users were given baths except Barry who was showered in his en-suite shower room. Staff used a flannel, body puff or sponge for washing. No one was asked to stand up to be washed in their genital area except for David who had been incontinent of faeces every time I observed him having a bath.

All service users had their own products which they did not share with anyone else.

Some staff wore gloves, and some did not.

All service users were given a wash in the evening. This varied from having their hands washed to a full all over body wash. David was sometimes given a bath in the day if he had been incontinent. On one occasion Barry was given a bath in the afternoon because he had been incontinent of faeces overnight, and it was thought that the shower he had in the morning was not sufficient to get him clean.

### **Hair washing**

Hair was washed every day in the bath or in the shower using either a shower head or a jug that was filled with water from either the tap or the bath. Barry used medicated shampoo and ordinary shampoo on alternate days. No one used separate conditioner.

### **Shaving**

All the male participants were shaved every day. Simon was given a wet shave whilst either sat on the toilet or in the bath. Barry was also given a wet shave whilst sat on the toilet. David was shaved with an electric shaver whilst sat on

his bed after he had his bath and was dressed. David was also shaved at other times of the day if he requested it by leading staff to his shaver.

None of the female service users had any hair removal carried out.

### **Brushing teeth**

All service users had their teeth brushed twice every day, in the morning before breakfast, and in the evening after dinner. Sometimes Barry had his teeth brushed after breakfast. Brushing generally lasted between 10 and 30 seconds. None of the service users were able to spit out the toothpaste.

### **Dressing**

At Fir Tree House, Simon and Barry left their en-suite bath or shower rooms after bathing to dress in their bedroom. At Primrose Cottage, Beth and Elaine wore a dressing gown after being dried and left the bathroom to get dressed in their bedroom. Mary and David were dressed in the bathroom.

Gemma kept her gloves on whilst dressing and told me that this was to protect her and the service user. No one else wore gloves whilst dressing.

Mary was the only service user who wore glasses.

### **Other**

All of the service users wore deodorant except Mary. None of the female service users wore make-up. I observed staff spraying Mary with perfume. Sometimes the female service users had their nails painted (the polish was always chipped when I saw it). All of the male service users owned aftershave. Sometimes it was used, and sometimes it was not. Barry had aftershave put on when he was going out. No one used body, face or hand cream. Mary, Beth and Elaine had their hair dried with a hair dryer, and Elaine's hair was sprayed with hair spray.

## **Toileting**

The first thing that staff got all service users to do when they entered the bathroom in the morning was to sit on the toilet. The period of time that service users were left to sit on the toilet varied. Sometimes staff immediately started to attend to shaving when Simon and Barry sat on the toilet. At other times, service users were left to sit on the toilet whilst staff were busy doing something else, such as running the bath and collecting towels. Service users were never left in privacy to use the toilet first thing in the morning (except Elaine who could get out of bed and take herself to the toilet).

Simon was continent and went to the toilet independently. Staff told me that he liked to play with the water in the toilet, and sometimes someone would stay nearby him whilst he used the toilet in order to check on him if he was a long time.

Barry was incontinent of urine and faeces. He wore pads when out, but not at home. Barry was prompted by staff to go to the toilet at regular times (after breakfast, after lunch, during the afternoon and after dinner), and when prompted he took himself to the toilet independently. He needed help to pull down his trousers and underpants and to do the button and zip up on his trousers when he had finished. Barry usually went to his en-suite shower room to use the toilet and left his room when he was finished.

Mary was incontinent of urine and faeces and wore pads at all times. She was taken to the toilet at specific times of the day and left to sit there for a while (up to half an hour). She was also taken to have her pad changed at specific times of the day (such as lunch time and before dinner). At times, the pad leaked (staff said that this was because it had not been put on properly).

David was incontinent of urine and faeces and wore pads at all times. His pad usually had urine and faeces in it in the morning. His pads leaked at times, making his clothes wet through.

Beth was continent and could go to the toilet independently during the day and at night time.

Elaine was continent and could take herself to toilet with prompting from staff.

This description of intimate care provided the foundation for more in-depth, theoretical analysis

## Appendix 21

### Exported list of codes from MAX qda July 2006

#### Code System

##### Care

- Comfort and pleasure
- Unpleasant or uncomfortable
- Care and concern
- Safety

##### Communication

- Interaction
- Service user communication
  - Emotion
  - Ways to communicate needing to go to the toilet
  - Control and choice
- Sexual connotations
- Staff communication
  - Attributing higher ability
    - Asking questions which cannot be answered
  - Telling you what will happen
  - Staff control
  - Sorry
  - Joint activity or task
  - Object of reference
- Words for body parts and products
- Words used to refer to intimate care
- Words used to refer to service users

##### Humour

##### Dignity and respect

- Open doors and privacy
- Naked
- Disinhibition

##### Research process

- My intervention (blue)
- Researcher distraction (green)
- Important - don't know where to code
- Things that I have noticed that have not happened

##### Rituals and tasks (the doing bit)

- All the same
- Routines
- Allocation of tasks
- Continence
- Functions and tasks involved in intimate care
- Hygiene good
- Hygiene Poor
- In/consistencies
- Physical examination
- Preparing
- Rushing and Time taken
- Shaving

##### Service user experience (the feeling bit)

- Choice

- Cooperation and independence
- Dependence
- Service user behaviour
- Staff perception
- Waiting
- Staff perceptions and experiences
  - Like / dislike
  - Physical demands on staff
  - Guidelines
  - Coping with intimacy
  - Empathy
  - First experiences
  - Gender of carer
  - Differences between permanent and agency staff
  - Staff comments
  - Standards and decision making
  - Training and skills



## **Appendix 22**

### **Code definitions exported from MAX qda on 11.05.06**

Code Care\Care and concern  
Creation Date 10/05/2006

This is when staff demonstrate concern or care for the service users or when they demonstrate lack of concern or care.

Code Care\Safety  
Creation Date 10/05/2006

These are things that staff say they do and are for probably for safety reasons and other observations related to safety.

Code Care\Comfies / comfort / pleasure  
Creation Date 10/05/2006

These are things that staff do, or say that they do for comfort or pleasure.

Code Communication\Interaction  
Creation Date 10/05/2006

Two way interaction involving action or communication by both staff and service user, or interaction that involves physical contact and therefore not only about communication.

Code Communication\Service user communication  
Creation Date 10/05/2006

This includes how staff interpret behaviours as communication and some examples from observations that could have been attempts to communicate.

Code Communication\Service user communication\Ways to communicate the need to go to the toilet  
Creation Date 10/05/2006

Ways in which service users let staff know that they want to use the toilet.

Code Communication\Service user communication\Control and choice  
Creation Date 10/05/2006

Things that service users do to exercise choice and control, or things that they do which staff or I have perceived as being a purposeful demonstration of choice making.

Code Communication\Sexual connotations  
Creation Date 10/05/2006

Staff comments which have sexual connotations.

Code Communication\Staff communication  
Creation Date 10/05/2006

Ways in which staff communicate and examples of communication with service users.

Code Communication\Staff communication\Attributing higher ability  
Creation Date 10/05/2006

This is when staff behave as if the service user has a higher ability than they probably do.

Code Communication\Staff communication\Attributing higher ability\Asking questions which cannot be answered  
Creation Date 10/05/2006

Examples of questions that staff ask service users even though they will not get an answer.

Code Communication\Staff communication\Staff control  
Creation Date 10/05/2006

These are methods staff use (consciously or unconsciously) to get service users to do something or to control them.

Code Communication\Staff communication\Telling you what will happen  
Creation Date 10/05/2006

These are examples of staff telling service users what is happening or what will happen next.

Code Communication\Staff communication\Sorry  
Creation Date 10/05/2006

These are examples of staff apologising to service users (direct observations only, not including interview data).

Code Communication\Staff communication\Joint activity / task  
Creation Date 10/05/2006

These are times when staff say something to suggest that intimate care is carried out as a partnership e.g. we'll get in the shower.

Code Communication\Staff communication\Object of reference  
Creation Date 10/05/2006

These are objects or actions that might indicate to service users what is going to happen next.

Code Communication\Words for body parts and products  
Creation Date 10/05/2006

These are words and phrases that staff use when talking about private parts of the bodily products.

Code Communication\Words used to refer to intimate care  
Creation Date 10/05/2006

These are words that staff use to refer to various aspects of intimate care.

Code Communication\Words used to refer to service users  
Creation Date 10/05/2006

Words and phrases that staff use to refer to service users or when speaking to service users.

Code Dignity and respect  
Creation Date 10/05/2006

Incidences that relate to dignity and things that staff have said about dignity - either the promotion of or lack of.

The Oxford English Dictionary (2002) defined respect as "a feeling of deep admiration for someone elicited by their qualities or achievements" or "due regard for the feelings or rights of others".

Dignity: "the state of being worthy of honour or respect".

Related to dehumanisation

Code Dignity and respect\Disinhibition  
Creation Date 10/05/2006

Service users' behaviours which suggest that they are disinhibited.

Code Dignity and respect\Naked  
Creation Date 10/05/2006

Observations of service users naked or partially clothed (at times when they did not need to be). And times when staff have attempted to cover a service user up.

Code Dignity and respect\Open doors  
Creation Date 10/05/2006

Times when bathroom doors are left open and when other people enter the room while someone is using the bathroom or unclothed.

Code Humour  
Creation Date 10/05/2006

Examples of humour used by staff and of service users and staff laughing or finding something funny.

Code Research process\My intervention (blue)  
Creation Date 10/05/2006

Things that I have done or examples of my interaction within the research setting.

Code Research process\Researcher distraction (green)  
Creation Date 10/05/2006

Things that have happened because I am there and incidences when I have caused a distraction.

Code Research process\Important - don't know where to code  
Creation Date 10/05/2006

Things that I think are important or interesting but I do not know, initially where to code. Coded here so that I do not forget about important data.

Code Routines, rituals and tasks (the doing bit)\Continence  
Creation Date 10/05/2006

Every reference to continence except routine toileting.

Code Routines, rituals and tasks (the doing bit)\Functions of intimate care  
Creation Date 10/05/2006

Codes Communication\Words used to refer to intimate care

What staff think service users get from intimate care and some of the activities that are included in personal and intimate care.

Possibly related to words used to refer to intimate care.

Code Routines, rituals and tasks (the doing bit)\Hygiene good  
Creation Date 10/05/2006

Examples of good hygiene or when staff talk about the importance of hygiene.

Code Routines, rituals and tasks (the doing bit)\Hygiene Poor  
Creation Date 10/05/2006

Observations of poor hygienic practices.

Code Routines, rituals and tasks (the doing bit)\Inconsistencies  
Creation Date 10/05/2006

Examples of when staff do things differently or the same.

Code Routines, rituals and tasks (the doing bit)\Physical examination  
Creation Date 11/05/2006

Examples of when staff have noticed something about the service users' physical health whilst carrying out intimate care.

Although there are only two entries to this code so far, I am keeping the code because the literature contains reference to intimate being used to carrying out physical examinations. I might find that there are more examples as I read back over the texts because this is a code that was added later on.

Code Routines, rituals and tasks (the doing bit)\Physical demands on staff  
Creation Date 11/05/2006

Examples which suggest that intimate care places physical demands on staff.

Code Routines, rituals and tasks (the doing bit)\Rushing / Time taken  
Creation Date 11/05/2006

This code includes times when staff appear to be rushing and observations of the amounts of time that activities take.

Code Routines, rituals and tasks (the doing bit)\Shaving  
Creation Date 11/05/2006

References to shaving and observations of shaving. Including observations of service users being cut from shaving. (I might need to do a word search for blood, bleeding and cut to see if there are any that I have missed.)

Code Service user experience (the feeling bit)\Waiting  
Creation Date 11/05/2006

References and observations, which suggest that service users, have to wait or have been left waiting.

Code Service user experience (the feeling bit)\Staff perception  
Creation Date 11/05/2006

What staff say they believe service users think or feel.

Code Service user experience (the feeling bit)\Choice  
Creation Date 11/05/2006

Examples of staff offering choice, where it seemed likely that the offer was genuine and that the member of staff would respond accordingly if the service user demonstrated a preference.

Code Service user experience (the feeling bit)\Cooperative / independence  
Creation Date 11/05/2006

Things that service users are able to do for themselves and times when service users co-operate with what they have been asked to do. This might need to be two separate codes.

Code Service user experience (the feeling bit)\Dependence  
Creation Date 11/05/2006

Things that service users are thought to be unable to do and are dependent on others for.

Code Service user experience (the feeling bit)\Service user behaviour  
Creation Date 11/05/2006

Behaviours which I think have the function of sensory stimulation (LaVigna, Functional analysis).

Code Staff perceptions and experiences\Coping with intimacy  
Creation Date 11/05/2006

Things that staff do or say which might be a way of coping with intimate care intimacy and things that they find unpleasant. Including staff's own explanations for how they deal with these things.

Code Staff perceptions and experiences\Empathy  
Creation Date 11/05/2006

Things that staff say that show they are thinking about the service users perspective or putting themselves in the service users shoes.

This code was added from the interview with James. After the first four interviews James was the only person who had shown empathy in this way. (I do need to go back and re-check the other interviews.)

Code Staff perceptions and experiences\First experiences  
Creation Date 11/05/2006

Things staff say about their first experiences of intimate care.

Code Staff perceptions and experiences\Gender of carer  
Creation Date 11/05/2006

Possible differences between make and female staff.

Code Staff perceptions and experiences\Differences between permanent and agency staff  
Creation Date 11/05/2006

Differences between permanent and agency staff as perceived by staff.

Code Staff perceptions and experiences\Staff comments  
Creation Date 11/05/2006

Things that staff have said unprompted. Including things said to me, seemingly as way of explanation. These could be things that staff think are important for some reason, or things that staff think I want to know about.

Code Staff perceptions and experiences\Standards and decision making  
Creation Date 11/05/2006

Things that staff appear to think are important about the way that they carry out intimate care and rationale they give for making decisions.

Code Staff perceptions and experiences\Training and skills  
Creation Date 11/05/2006

How staff learn what they need to do.

Code Routines, rituals and tasks (the doing bit)\Allocation of tasks  
Creation Date 11/05/2006

How staff decide who does what. New code from analysis of focused observations. Need to go back and check other texts.

Code Staff perceptions and experiences\Guidelines  
Creation Date 11/05/2006

Everything about support guidelines.

Code Research process\Things that I have noticed that have not happened  
Creation Date 11/05/2006

Things that I have noticed that perhaps I think should have happened or I wonder why something didn't happen.

Code Communication\Emotion  
Creation Date 10/05/2006

These are some examples of observations made about facial expressions or behaviour which might be indicative of how the service user feels. The observation segments that have been coded here include examples of when I have interpreted sounds to be communicating emotion. However, it could be that something else was being communicated.

Code Routines, rituals and tasks (the doing bit)\Preparing  
Creation Date 11/05/2006

Examples of activities that staff carry out to prepare for providing intimate care.

## Appendix 23

### Summary of findings from concept analysis of dignity

A review of the literature on dignity and dignity in health and social care was conducted in order to carry out concept analysis. Various components of dignity were suggested by different authors, and these are listed below. Concept analysis was carried out with recourse to the data that had been collected in this study, and the results of this analysis relate to the use of the term dignity in health and social care settings, and in relation to the subjective dimensions of self-regarding and other-regarding dignity.

#### **Mairis (1994)**

- Exerting control
- Capable of understanding information
- Capable of making decisions
- Feeling comfortable with status quo

#### **Dworkin (1995)**

- Acknowledge critical interests

#### **Haddock (1996)**

- Self-respect
- Self-confidence
- Self-control
- Control of environment
- Pride of self
- Trustworthy
- Happy with self
- Humorous
- Autonomous
- Independent
- Private
- Positive self-identity
- Integrity of identity

#### **Shotton and Seedhouse (1998)**

- Feeling foolish
- Feeling incompetent
- Feeling inadequate



- Feeling unusually vulnerable
- Failing to achieve what we would normally
- Match between circumstances and competencies

#### **Mann (1998)**

- Not being significantly recognised
- Being seen but as member of group
- Violations of personal space
- Humiliation (being singled out)

#### **Statman (2000)**

- Humiliation
- Rejection
- Exclusion
- Social inclusion

#### **Jacobs (2001)**

- Respect for personal autonomy

#### **Fenton and Mitchell (2002)**

- Physical, emotional and psychological comfort

#### **Widang and Fridlund (2003)**

- Being seen as a whole person
- Being respected (being treated as a person and not an object)
- Being seen as trustworthy (in terms of own life situations and illness)
- Being respected as a person with unique needs
- Ignoring competence
- Exposed to ridiculing or patronizing comments

#### **Nordenfelt (2004)**

- Integrity
- Autonomy

#### **Franklin et al (2006)**

- Respect for person as individual

Some of these ideas essentially refer to the same thing, and have been collapsed down into nine properties (see figure A.3). The aim was for the components of these properties to have internal homogeneity and external heterogeneity because this is what gives properties utility (Guba and Lincoln, 1981).

**Figure A.3: The components of the nine properties of dignity**

<b>Property</b>	<b>Evidence of the property taken from the review of the literature</b>
Being treated like a person, not an object	<ul style="list-style-type: none"> <li>• Being respected (being treated as a person and not an object)</li> <li>• Violations of personal space</li> <li>• Private</li> </ul>
Being treated as a whole person	<ul style="list-style-type: none"> <li>• Being seen as a whole person</li> <li>• Not being significantly recognised</li> <li>• Integrity of identity</li> </ul>
Being treated as an individual	<ul style="list-style-type: none"> <li>• Being respected as a person with unique needs</li> <li>• Being seen but as member of group</li> <li>• Acknowledge critical interests</li> </ul>
Being treated as having equal worth	<ul style="list-style-type: none"> <li>• Feeling comfortable with status quo</li> <li>• Feeling inadequate</li> <li>• Self-respect</li> <li>• Self-confidence</li> <li>• Pride of self</li> <li>• Happy with self</li> <li>• Positive self-identity</li> </ul>
Being treated as belonging	<ul style="list-style-type: none"> <li>• Rejection</li> <li>• Exclusion</li> <li>• Social inclusion</li> </ul>
Being allowed control and autonomy	<ul style="list-style-type: none"> <li>• Exerting control</li> <li>• Feeling unusually vulnerable</li> <li>• Autonomy</li> <li>• Respect for personal autonomy</li> <li>• Self-control</li> <li>• Control of environment</li> <li>• Independent</li> </ul>
Having competencies realistically acknowledged	<ul style="list-style-type: none"> <li>• Match between circumstances and competencies</li> <li>• Capable of understanding information</li> </ul>

	<ul style="list-style-type: none"> <li>• Capable of making decisions</li> <li>• Feeling incompetent</li> <li>• Failing to achieve what we would normally</li> <li>• Being seen as trustworthy (in terms of own life situations and illness)</li> <li>• Ignoring competence</li> </ul>
Not being made to feel foolish, embarrassed, degraded	<ul style="list-style-type: none"> <li>• Feeling foolish</li> <li>• Exposed to ridiculing or patronizing comments</li> <li>• Humiliation (being singled out)</li> </ul>
Being given a state of physical, emotional and spiritual comfort	<ul style="list-style-type: none"> <li>• Physical, emotional and psychological comfort</li> </ul>

## **Appendix 24**

### **Example of a scenario that could be used to encourage empathy in staff training**

Just imagine for a minute that you wake up one morning in bed, and as usual need to go the toilet. The toilet is in your en-suite bathroom, which is just five metres from your bed, but you have difficulties walking and can't get out of bed without help. Staff arrive at your house at 7.00am and you can hear them talking in the hallway. You really need to go to the toilet, but no one comes to help. You would call for help, but you can't speak. Half an hour later someone opens the bedroom door and comes in. But it is too late, and you have wet the bed. The member of staff helps you to the toilet. You sit on the toilet as instructed – but you don't need to go any more. Your nightclothes are taken off and you are left to sit on the toilet completely naked. The door between the bathroom and the bedroom is open and the member of staff busies herself in your bedroom. Another member of staff knocks on the bedroom door and comes in. They say good morning to you and then chat to the other staff for a few minutes before leaving. When the staff has finished what she was doing in your bedroom, she comes and asks you to get in the shower.

## Appendix 25

### **‘Conditions and consequences’ category: ‘resources and skills’**

In order to maintain dignity adequate resources, time, equipment and an appropriate environment needed to be available. Staff also needed to have the necessary skills to carry out intimate care and to interact with the service user in a way that would maintain their dignity.

The themes in this category were:

- Training and skills
- Guidelines and policies
- Environment and equipment
- Easy or difficult
- Agency staff
- Gender of carer
- Physical demands on staff

#### **Training and skills: *‘just a question of common sense’***

None of the staff who participated in this study had received any formal training on intimate care. Some members of staff thought this lack of training was a problem.

*James talked at some length prior to the interview about how he thought that the research I am doing is important because of the lack of training that is offered for intimate care.*

However, the view that intimate care is a skilled task, and therefore requires training, was not shared by all staff.

*Denise: I just think that personal care is just a question of common sense.*

Staff based the way that they carried out intimate care on their previous experiences of providing intimate care for their own family, children and for themselves.

*Julie: Okay. So how do you think that you have known and worked out what you do have to do when you are giving personal or intimate care?*

*Sally: Erm, well it's one from doing it for myself and maintaining my own personal care and making sure I'm clean and tidy.*

*Julie: Right*

*Sally: My children. And also my partner and watching him and seeing what he does to keep himself clean and tidy as well so it's just from there.*

*Julie: Okay, yeah*

*Sally: But it is mainly I try and do it how I'd like it to be done as well.*

However, the manager of Fir Tree House did not think that it was appropriate to base the way that intimate care was carried out on the way that care is provided to children.

*Frank told me about some of the discussions that had taken place with Primrose Cottage about intimate care. One member of staff compared it to looking after children. Frank seemed to think that this was not strictly the most appropriate way to see it.*

Staff also learnt what to do by reading guidelines and shadowing other staff.

*Julie: Okay. And so how did you come about knowing what to do?*

*Sharon: Well my first, when I got here they showed me the, they had those agency files, they were a bit older then. So I read them. But then my first morning I, my first proper morning I shadowed Faye round every single one. Which we don't do enough here but I did it, and it really helped me. Especially Faye has been here for so long and knows, knows them.*

### **Guidelines and policies: 'due to be reviewed'**

There were few policies in place relevant to intimate care at Primrose Cottage, as the manager of the home explained in the following field notes which were taken from an informal interview;

*I later asked Frank about what policies Primrose Cottage had in relation to personal and intimate care. There were no policies specifically related to intimate care except for cross gender care. Frank told me that the policies that would be relevant were on 'moving and handling' and 'physical interventions' and that he would get copies for me.*

The policies that were available were all out of date;

*I asked Jenny if I could read the policies. Jenny said that they were all out of date and were currently being reviewed by social services.*

At Fir Tree House there were more policies in place regarding intimate care, and there was also a procedure in place for them to be regularly reviewed by the service provider. In addition, the guidelines that were written within the home were kept up to date; ,

*Sally: If anybody brings to my knowledge anything at staff meetings or whatever, that Barry is doing this a little bit different or, or whatever. And then we can change them [guidelines], sort of accordingly.*

At Fir Tree House, guidelines had been written for teeth cleaning for every service user. However, staff were not always aware of the guidelines that were in place as this example shows;

*Julie: Are there any guidelines for teeth cleaning?*

*Denise: Not as far as I know. I mean we use an electric toothbrush.*

Barry's night time routine had been changed and the guidelines had been updated accordingly. However, some of the staff had not read them.

*The member of staff on the night shift does not know new guidelines and has got Barry up at 6am instead on 3am to use the toilet.*

**Environment and equipment: 'Stupid place to put a front door, right by the toilet'**

Maintenance of dignity was partly dependent on having the appropriate environment and equipment.

*Whilst I was talking to Frank in the office, Elaine came down the hallway with her trousers pulled down (having just used the bathroom). Frank ran out to help her and when he came back he said "Stupid place to put a front door, right by the toilet".*

Memo: Frank emphasises the importance of the environment meeting the needs of the individual.

When equipment was broken, this impacted on the service users' experience.



*Mary's usual hoist is broken so she has to wait until last before anyone gets her out of bed.*

Service users had to share bathrooms, and therefore at times, had to wait until one was free for them to use.

There was no way of stopping other service users entering the bathroom, except by locking the door which some members of staff did not think it safe to do.

The bathroom looks clinical and not the kind of place that might be relaxing, as this entry to my field notes illustrates;

*I notice how clinical the bathroom looks. The walls are tiled white and there is a noisy fan. The bath is a special mobility aid bath that is positioned in the middle of the room. The bath does not look inviting and there are no bubbles in it.*

**Easy or difficult: 'they are quite simple really to look after'**

Some service users were seen as being more 'easy' to support than others;

*Lorraine asked staff who they would like to get up. Bella joked about Josie doing four and Josie said that would be ok because they were all "easy".*

Sally told me that decisions about allocating staff to support service users were based on how 'easy' or 'difficult' service users were to support, and the amount of work that was involved;

*Sally: Yeah...usually key clients work with key workers and stuff like that. Nobody has got any favourites or anything like that it's just a matter of, you know if you do Simon, normally you end up with Andy as well because they are quite simple really to look after. They're not quite as in detail as what Barry could be, because Barry sometimes can be quite messy and it takes a long time to change all his bedding and all that kind of thing so.*

This might have suggested that carrying out intimate care could be a skilled activity because of the specific needs of individual service users.

**Agency staff: 'with agency staff it is different'**

Agency staff were often thought, by permanent staff to be liked less by service users and not to understand service users as well. This was thought to impact on the quality of care provided. In the following excerpt, Sally explains that she does not like allowing agency staff to carry out intimate care unless they had shadowed more experienced staff, but that sometimes there was no choice;

*Sally: and not only, I mean with agency it is different because you have to, we are relying on them to help us, we have to let them go in there and not shadow them and that kind of thing (clears throat). But with new staff I don't let them loose (emphasis and higher pitch) on the guys until they have been here a week and I know that they, they have watched and that they understand and they've read the guidelines.*

*James: I don't know. Err, or perhaps Barry was just thinking oh 'I'm not going to do it for you', you know, 'I don't know you'. Which to be honest, is possibly the way I'd feel, you know, I'm never quite sure of the understanding of the guys, but, yeah, I think I'd possibly get annoyed if someone new was doing intimate things.*

This theme suggested that it is better to have sufficient permanent staffing numbers so that there was no need to employ agency staff. Or, that agency staff should receive a thorough induction before they begin carrying out intimate care.

### **Gender of carer**

At Fir Tree House, a male member of staff supported Mary to be hoisted onto the toilet when the other female staff was busy. If there had been another female member of staff present, this would not have happened.

An issue was also raised by one member of staff about the ability of female staff to shave men, as the following excerpt from an interview shows;

*James: I mean, (pause) I don't know if this is the sexist angle. But I don't know how many women have shaved men before.*

*Julie: M h*

*James: Because it's not the same as shaving legs.*

*Julie: No*

*James: Uhm, it is kind of, I mean obviously it is the same, it is the same principle but it is a bit different from that. And I'm not sure that you know everyone can do it that well. I've never been shown how to do it.*

*Julie: Mh*

*James: Uhm perhaps I have a little inclination because I'm a fella. Uhm again it's different for me to shave a man than for me shave myself.*

### **Physical demands on staff: 'I'm too tired'**

In the final theme in this category, intimate care was seen to be physically demanding and staff needed to have a certain level of fitness to carry it out. Staff were observed to be out of breath by the way they were 'huffing and puffing' during intimate care;

*Caroline has kidney problems and this has clearly been physically demanding for her and sometimes painful.*

*Joan sounds like she is exerted.*

The following excerpt suggested that the demands intimate care placed on staff could have affected their motivation to carry it out.

*Faye sighs and says [to me] 'I don't want to do this this morning...I'm too tired'.*

## **Summary**

These themes have illustrated some of the ways in which dignity could have been affected by the skills of the people providing the care, and also by the resources that were available in terms of staffing, equipment and the environment of the care setting.

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