

THE UNIVERSITY OF HULL

**Investigating the experiences of people with learning disabilities
in Accident & Emergency from a carer perspective**

being a Thesis submitted for the Degree of

Doctor of Clinical Psychology

in the University of Hull

by

Elizabeth Piper B.Sc, M.Sc, MBA

May 2008

ACKNOWLEDGEMENTS

I should like to thank all the service users and carers who gave so freely of their time and were prepared to recount their experiences for this work to be produced.

I am grateful to Dr Lesley Glover & Dr Peter Oakes from Hull University.

I appreciate the support and encouragement provided by my colleagues especially Barbara Patton.

Finally, thank you to my family Mark, Alex & Chris who have been very understanding over the past few years.

ABSTRACT

Primary and secondary health services have a duty to provide for the health needs of people with learning disabilities. Previously this group of the population may have experienced segregated and/or a lack of adequate health services. However a combination of legislation, Government policies and guidelines and improved advocacy has placed pressure on primary and secondary healthcare to provide more equitable services. Much of the research already undertaken has focused on primary care or planned admissions within mainstream hospital. The following research sought to investigate emergency healthcare - as delivered via Accident & Emergency - from the perspective of the carers of people with learning disabilities. The work was undertaken in two separate A&E departments. An Interpretative Phenomenological Approach was used to analyse interviews undertaken with carers. Some of the findings which emerged were in keeping with past literature. However some differed from that previously reported - major concerns were not raised by carers about consent or staff attitudes, although the relationship staff had with both service users and carers was considered to be fundamental to a high quality service. The themes identified included Interactions that are valuing, Emotional responsiveness, Support, Compliance and Responsibilities. Given accounts in previous literature, most participants were surprisingly positive about their experiences.

CONTENTS

CHAPTER 1

INTRODUCTION	1
--------------	---

CHAPTER 2

LITERATURE REVIEW	4
1.0 Experiences of Service Users, Carers and Hospital Staff	4
1.1 General	4
1.2 Staff attitudes towards learning disabilities	7
1.3 Staff attitudes within A&E	8
1.4 Communication	9
1.5 Recognition and management of pain	9
1.6 Consent to treatment	10
1.7 Waiting times	11
2.0 Support	12
2.1 Support role of carers	12
2.2 Liaison nurses/services	13
3.0 Carers & Service Users as Research Participants	14
3.1 Carers as participants	14
3.2 Service users as participants	15
3.3 Service users as evaluators	16

CHAPTER 3

AIMS & RATIONALE	18
------------------	-----------

CHAPTER 4

METHODOLOGY	19
-------------	----

1.0 Overview	19
--------------	----

2.0 Design	20
------------	----

2.1 Choice of qualitative approach	20
------------------------------------	----

2.2 Choice of Interpretative Phenomenological Analysis	22
--	----

2.3 Other data collection	24
---------------------------	----

3.0 Setting	25
-------------	----

4.0 Participants and Recruitment	26
----------------------------------	----

4.1 Inclusion criteria	26
------------------------	----

4.2 Potential participants	27
----------------------------	----

4.3 Exclusion Criteria	28
------------------------	----

4.4 Participant Information	28
-----------------------------	----

5.0 Measures	33
--------------	----

6.0 Procedure	34
---------------	----

7.0 Researcher	36
----------------	----

8.0 Analysis of transcripts	37
-----------------------------	----

CHAPTER 5

RESULTS	43
---------	-----------

1.0 Interactions that are valuing	44
1.1 Involving the service users	44
1.2 Listening to carer/ Liaison Nurse advice	47
1.3 Empowerment vs powerlessness	49
1.4 Keeping carers informed	50
2.0 Emotional responsiveness	53
2.1 Nurturing (caring)	53
2.2 Empathy & Understanding	55
2.3 Recognition	58
3.0 Support	58
3.1 Support from the carer to service user and to staff	58
3.2 Equipment	59
3.3 Liaison Nurse	60
4.0 Compliance	63
5.0 Responsibilities	68
5.1 Risk taking & management	68
5.2 Medical care including pain issues	70

CHAPTER 6

DISCUSSION 72

1.0 Current findings and their relationship to past research 72

1.1 Interactions that are valuing 72

1.2 Emotional responsiveness 73

1.3 Support	77
1.4 Compliance	79
1.5 Responsibilities	80
1.6 Themes identified in other research	80
1.7 Summary of clinical implications	81
2.0 Reflexive Analysis	82
3.0 Strengths & Limitations	84
4.0 Implications for further research	87
4.1 Liaison nurse posts	87
4.2 Views of verbal service users about A&E	88
4.3 Views of non verbal service users	88
CHAPTER 7	
CONCLUSION	89
REFERENCES	90
APPENDICES	100

TABLES

Table 1: Participant and Service User Details	30-32
Table 2: Examples of searching for emerging themes from the original transcripts	38-39
Table 3: The development from initial to master theme	42
Table 4: Master and sub themes	43

CHAPTER 1

INTRODUCTION

An estimated 2% of the UK population has a learning disability and this figure is on the increase (Lancaster University 2004). The definition of 'learning disability' can vary and for the purpose of this thesis the Department of Health's definition of a lifelong significantly reduced ability to learn new or complex information (intellectual impairment) together with a reduced ability to cope independently has been used ('Valuing People' Department of Health 2001b).

Over the past 20 years there has been considerable change to the way in which people with learning disabilities access medical care. Prior to this many people with cognitive impairments lived in institutions, where their health care needs, if addressed, were treated on site. Since closure of such institutions there have been more people with learning disabilities using primary care and hospital services. In addition to this, general medical techniques are more advanced so that babies with quite complex physical health needs, often accompanied by learning disabilities, are more likely to survive and the longevity of the learning disabled population as a whole has increased (Patja et al. 2000).

Since the Community Care Act (National Health Service & Community Care Act 1990) there have been a number of Government initiatives focusing on the health of people with learning disabilities. 'Signpost for Success' (Department of Health 1998) emphasises the rights of people with learning disabilities to health services and outlines good practices that will support this. 'Once A Day' (Department of Health 1999a), published the following year, is a clearly written guide of good practice covering all aspects of healthcare – including the common issues faced by people with learning disabilities within general hospital. There are various reports as to the levels of additional healthcare needs people with learning disabilities have and how this relates to the type and severity of the disability. However there is agreement that there is disparity in both health status and in healthcare received by this group of the population. This

disparity is linked to a number of factors including additional physical health issues, poor understanding by people with learning disabilities as to their own health needs and rights and to social deprivation (Scheepers et al. 2005, 'Valuing People' Department of Health 2001b, Emerson and Hatton 2007). In 1995 the 'Health of the Nation Strategy' (Department of Health 1995) described plans to reduce heart disease, cancer, sexual health problems, mental illness and accidents amongst people with learning disabilities. The concern of the Department of Health at the time was that people with learning disabilities were not receiving early intervention, which meant that potentially treatable illnesses were able to progress to a stage where treatment was either not possible or less effective. Turner & Moss (1996) cautioned that other health needs, not included in the Health of the Nation document, should not be overlooked. Studies carried out since the Community Care Act indicate that between 75% and 80% of people with learning disabilities surveyed, had significant problems which required, but were not receiving, adequate medical intervention (Howells 1986, Wilson & Haire 1990, Rimmer & Whitfield 1995). In 2007 the Department of Health announced its intention to launch an inquiry into the death of six people with learning disabilities, who it was claimed by the report 'Death by Indifference' (Mencap 2007) received inadequate healthcare.

All the above, raise issues for primary and acute health care services which effectively have an additional population and one which they are often ill-equipped to support (Marshall et al. 1996, Lindsey et al. 1993). During the 1990's various recommendations were made as the result of research into the health needs of this population e.g. that managers and educators should address the needs of current qualified general nurses who may have limited experience of people with learning disabilities (Slevin 1995). However the findings of 'Facing the Facts' (Department of Health 1999b) resulted in a press release by John Hutton, then Minister for Health, in which it was stated, "Little progress had been made since the 1990s to transform services in pursuit of significantly improved quality of life". (Hutton, 1999 p.1)

The Royal College of Nursing (2006) has since set out its own guidelines for meeting the health needs of people with learning disabilities, which takes into consideration health needs, policy and law including consent and also offers advice on supporting

access. Others have written very practical articles designed to support nurses in providing high quality care (Williamson & Johnson 2004).

The Disability Discrimination Act (2005) makes it unlawful for those providing a service to treat people with intellectual or physical disabilities less favourably than they would others. Thus there is a need for NHS services to ensure that they are meeting the health needs of people with disabilities, not only because of Department of Health guidance but also in order to satisfy legislation. Some of the issues and potential resolutions are outlined in the document 'Doubly Disabled - Equality for disabled people in the new NHS access to services' (Department of Health 1999).

'Valuing People' (Department of Health 2001b), as well as emphasizing the rights of people to access mainstream hospital services, states that it is essential for the views of people with learning disabilities to be taken into consideration when services are being planned and evaluated. This was also recommended in the accompanying publication 'Nothing About Us Without Us' (Department of Health 2001a), developed by service users. This is a complex area, as people with global learning disabilities by definition have a cognitive impairment, often with accompanying communication difficulties, which makes consumer satisfaction studies problematic. Over the past 10 years there has been a burgeoning of research considering the experiences and needs of people with learning disabilities accessing mainstream hospital services. However comparatively little has been written about their experiences of Accident and Emergency (A&E). This is of concern as it is emergency treatment and unplanned admissions that appear to be most problematic for this client group and their carers (Piper & West 1998).

CHAPTER 2

LITERATURE REVIEW

This chapter has been divided into 3 sections: a review of service users', carers' and staff's experience of healthcare; a review of the literature identifying potential sources of support and finally consideration of the issues raised when obtaining the views of carers and service users.

1.0 Experiences of Service Users, Carers and Hospital Staff

1.1 General

A number of papers have sought to identify the experiences of those receiving and those providing physical health care. Cumella & Martin (2004) used consensus development conferences involving service users, their families, professional carers and others to explore the issues facing people with learning disabilities in hospital settings. Problems of communication and lack of information, the reliance on carers and the failure to adapt to service users' specific needs were all raised as issues from the service users' and carers' perspectives. Hospital staff felt unsupported by the community services and lacked training around communication with people with learning disabilities. A consensus development conference can be very valuable in developing solutions to commonly presenting problems through mutually agreed good practice guidelines. These by the nature of the approach will be based on people's shared experiences. The question arises as to whether the term 'learning disabilities' refers to a group sufficiently homogeneous to be able to provide common solutions. The term includes individuals with a wide range of cognitive impairments and a vast array of associated physical health and behavioural factors. There is therefore scope also to explore people's individual experiences and perceived needs. There have been a number of studies, which have sought to explore general access to healthcare for people with learning disabilities, in which carers and service users have been consulted along with

other stakeholders, including GPs, practice nurses, learning disability teams, staff in acute care and commissioners. For example Alborz and colleagues (2005) identified barriers to healthcare as including communication difficulties, inadequate facilities, rigid procedures and lack of specific skills of hospital workers. Corbett et al. (2003) described a number of concerns including the need for carer support to hospital staff, communication difficulties, lack of knowledge about consent to treatment and an absence of health promotion education to service users and carers. The body of research appears to have mostly sought views from verbal service users and those who are non verbal are often not consulted.

Whilst there is this growing literature about people with learning disabilities' experiences in the primary care setting and in some areas of acute services, there is little literature relating to the use of emergency healthcare, with the exception of that detailed below. In 2005 Brown recommend the need for emergency services to develop their knowledge and skills and to engage in partnership working with specialists in learning disabilities. In 2006 & 2007 Sowney & Barr published their findings from focus groups run with A&E nurses. The two themes they describe as emerging from their work related to a lack of knowledge about learning disabilities on the part of staff and their subsequent reliance on carers. Staff were describing feelings of fear and vulnerability as a result of their lack of knowledge. The above research has mainly focused on staff experience and perception.

In 1998 Piper & West investigated the experience of carers and verbal service users across a community and acute NHS Trust. Participants raised a number of concerns that were particularly pertinent to A&E and subsequently Piper (1999) interviewed A&E staff including nurses, doctors, receptionists and porters to gain their perspective. Four main areas of concern were identified from these two studies: communication, recognition and management of pain, consent to treatment and waiting times. These areas correspond with those identified in the literature and there were some unique issues for A&E.

- Admissions are unplanned therefore neither service users nor staff group can be specifically prepared -as can be done with planned admissions.

- Resources e.g. communication tools that might have been developed for specific individuals' past admissions are unlikely to be available to A&E staff
- Providing emergency treatment may require very swift action minimizing the time available for communication
- Admissions can occur throughout the night and therefore specialist staff may not be available to offer support.
- The unified medical records that may contain useful information about a service user's diagnosis, health status and, in some districts, other personal information such as specific fears, communication abilities - are not always available to A&E staff.
- Many people feel exceptionally vulnerable or fearful and may be in pain following an accident or injury and people with learning disabilities are no exception to this. They may, however, not express their fears or pain in a way that is understood or easy to manage and their levels of communication may be further impaired as a result of trauma.

Following these studies (Piper & West, 1998 and Piper, 1999) a specific package of training and resources to A&E staff and feedback to service users and carers was implemented in one particular A&E. This package included a flag system on the reception computer to identify people with a learning disability which then signposted A&E staff to a client profile sheet; training by specialist Learning Disabilities staff in Total Communication; the development of pictorial materials to aid explanation of procedures; identification of nurse staff from both A&E and Learning Disabilities with an interest in liaising and the provision of a 24 hour telephone service for Learning Disabilities staff to advise colleagues in A&E if required. This latter service was subsequently replaced by a Learning Disability Liaison Nurse. It was not clear whether the issues raised in these two studies were specific to a particular hospital, there was no planned evaluation for the package of change and no attempt was made to gain the views of non-verbal service users.

In addition to the above research, protocols and guidelines have been suggested by those working under the umbrella of Access to Acute Care (A2A) for various hospital departments including A&E (e.g. those produced by North Staffordshire Hospitals and Combined NHS Trusts, undated).

1.2 Staff attitudes towards learning disabilities

Many studies indicate that healthcare professionals may have very little experience of people with learning disabilities and this level of ignorance can lead to the formation of non-helpful attitudes. For example Barr (1990) noted that student nurses were uncertain about people with learning disabilities as regards issues of normality and aggression. 47% of the 74 registered general nurses questioned by Slevin & Sines (1996) perceived people with learning disabilities to be more aggressive. Other authors have described the negative views of the medical profession towards learning disability (Nurse et al. 1990). Gill et al. (2002) reported positive attitudes towards learning disabled patients as reported by GPs. However this was a self report measure with a 51% response rate and results may not have reflected the views of the non respondents nor matched the opinions of these GP's patients. This study also found no link between attitudes and learning disability training or non professional contact. There is conflicting evidence as to whether such contact leads to more positive attitudes, although Yunker and Block (1986) on reviewing some studies determined that 70% of respondents indicated an increased positive attitude with increased contact. Wishart and Johnston (1990) produced results which agreed with this and Slevin & Sines (1996) reported that the student nurses in their study had more positive attitudes to people with learning disabilities if they had higher amounts of contact with this group of the population. Furthermore they found that nurses educated to a higher level who had undertaken courses in behaviour or social science, had more positive attitudes about learning disabilities. However professional experience of working with people with a learning disability may be minimal for many general nurses (Shanley & Guest 1995). There is discussion in the literature about the positive effects of the nursing syllabus post Project 2000 as it increased the learning disability component (e.g. Boarder 2002). Prior to this it was not uncommon for student nurses to be offered either a placement in learning disabilities or a placement in mental health and many opted for the latter – despite the fact that there is evidence that staff were not confident in working within learning disabilities. For example McConkey & Truesdale (2000) found therapists and nurses less confident in dealing with people with learning rather than physical disabilities. As these researchers and Shanley & Guest (1995) have pointed out, it may be the type of contact and the resulting experience that is the critical factor that impacts upon attitude. Darbyshire (1993) described the difference in student nurses' responses

to a forthcoming placement in a unit for children with profound and multiple disabilities. “Some looked forward to the experience and found this type of nursing a challenge to their creative, caring abilities. For others, the experience provoked feelings of almost unmanageable sadness, helplessness and even disgust or repulsion. It is essential to emphasise that these students were being painfully open about their feelings towards these children and were often deeply ashamed of their negative reactions.” (Darbyshire 1993, p42). This quote emphasises that the attitudes of nurses and probably other healthcare professionals are likely, at least initially, to be no different to those of the general population. There are implications for supporting staff as regards how they feel about issues of disability prior to beginning training and how they might work most effectively with this group of the population.

1.3 Staff attitudes within A&E

It may well be that service users without disabilities, accessing A&E are dissatisfied with staff attitudes. Nyström et al. (2003) used a hermeneutic approach to examine the experiences of nine patients (from the general population) and nine nurses in emergency care. One identified theme was that nursing care in this setting can be fragmented with different nurses responsible for different aspects of care e.g. triage nurse for initial assessment. Another theme was that staff seemed to place value on completing nursing tasks swiftly. This led to the emphasis of *care* being on practical nursing care rather than aspects of *caring* such as support and understanding. The requirement for swift clinical intervention, the numbers of people using the service and the ongoing potential for further incoming emergencies, places pressure on staff to focus on practical procedures and for service users to be ‘good’ patients. In fact the study found that nurses were likely to give additional time to these ‘good’ patients and spend less time with people who complained. As people with learning disabilities often require additional time e.g. for communication; can respond better to continuity i.e. same nurse and may have additional needs which prevent them presenting as model/good patients, one could anticipate that the experience of both patients and staff could be negatively affected by the presence of a learning disability.

1.4 Communication

Many of the studies investigating the experiences of service users, carers and hospital staff have identified communication as a key issue. Given that communication problems exist, it is therefore unsurprising that some research reports that hospital staff communicate almost exclusively with the carer who is present (e.g. Mental Health Foundation 1996). 50% of the nurse respondents in the Slevin & Sines study (1996) reported that they did not feel competent when communicating with someone with a learning disability compared with 28% who did. Similarly research conducted with palliative care staff determined that 80% had concerns about communicating with a person with learning disabilities (Tuffrey-Wijne et al. 2005). The A&E staff interviewed by Piper (1999) said that they were uncertain how best to communicate and were concerned about appearing patronizing. The issue may not be specific to service users with a learning disability. The A&E nurses in a study by Byrne & Heyman (1997) did not take time to communicate with any of their patients. Their rationale was that they were aware of patient anxiety and considered that the most effective way to manage this was to hasten people's progress through the department and thus speed their removal from the anxiety provoking environment. An alternate solution might be to spend more time with the patient explaining and calming, but Byrne & Heyman point out that A&E nursing attracts individuals who feel confident in a fast paced setting, characterised by brief encounters with a wide variety of patients.

1.5 Recognition and management of pain

The literature around pain, including theories of pain, pain signals, pain sensitivity and individuals' own perceptions, indicates that this is a complex area that involves biological (neuronal and physiological) and psychological (cognitive and emotional) components. McCaffrey & Beebe (1994) suggested that the bottom line for practitioners is that "pain is what a person says it is". The difficulties arise when people either cannot verbally describe this or, if they are able to, may not have an extensive 'pain' vocabulary. Pain questionnaires usually rely heavily on descriptive phrases to determine the type of pain. Additionally a person's pain threshold level may be so significantly raised that problems go unrecognized. There are examples within the literature of the most serious consequences of this. For example post-mortems on people with learning disabilities indicated in one study (Cole et al. 1994) that there was a higher than

expected level of deaths as a result of volvulus (acute abdominal problem), that ordinarily one might have assumed would be diagnosed from patient reports of abdominal pain. In 1993 Biersdorff used third-party reporting to gain information about accidents or illnesses sustained by 123 people with developmental disabilities. The results suggested that 25% of participants showed elevated levels of pain threshold, whilst 11% appeared to have lower than normal pain thresholds. Thus being able to recognize pain, in order to be alerted to potential injury/illness as well as to ensure appropriate pain relief, may be complicated for staff treating people with learning disabilities. Part of the difficulty with this area, arises because of staff's unfamiliarity with alternative forms of communication and therefore their inability to explore with a service user the location, nature and severity of any pain experienced. Another issue also related to this, is the potential lack of knowledge about disabilities such as autism where pain signals may be more difficult to recognize. Kerr et al. (2006) summarised issues that face care staff in recognising and managing pain for people with learning disabilities and dementia. Hospital staff face similar issues and are further disadvantaged, operating in situations where there is limited time to build up a relationship with the service user and where they will have to rely quite heavily on carers' expertise in pain behaviour. In one study carers complained that hospital staff were not responding to the carers' opinions that the service users were in pain and consequently carers claimed that pain relief was not administered when it should have been (Piper & West 1998). Foley and McCutcheon (2004) suggested that nurses in the emergency situation will not have enough background knowledge about an individual with learning disabilities to use observation or self report to investigate pain and recommended that carers are involved in this process. There has been some work undertaken to develop self report measures of pain suitable for people with learning disabilities. For example Bromley et al. (1998) found that the sample of people with learning disabilities they assessed, could indicate pain location (on a body map) and pain intensity (using a colour scale) from photographs of others.

1.6 Consent to treatment

'Valuing People' (Department of Health 2001b) emphasizes that the Government is committed to improving issues of consent to treatment. This is acknowledged as being a difficult area for staff who are unaccustomed to working with people who may rely

more on non-verbal communication. Following the Court of Appeal's ruling that people who lack the capacity to consent to hospital admission cannot be assumed to have agreed to it on the grounds that they did not object (R v Bournewood 1998) and the Mental Capacity Act (2005), the legal position as regards consent should be clear. In 1999 Hart described the confusion that existed for some professionals who were continuing to seek consent to treatment from the carer of an adult with a learning disability. This was even occurring even when the service users were verbally capable of providing, or withholding, consent themselves. Piper & West (1998) & Piper (1999) highlighted that there were misconceptions and confusion for carers and professionals around this issue - both staff and carers believing that carers had the right to consent on behalf of adults with learning disabilities. Furthermore Hart (1999) stated that when consent was sought from the person with a learning disability it was "primarily being sought as a legal requirement, and rarely as a strategy for ensuring people with learning disabilities understand the nature of their forthcoming treatment" (Hart 1999 p20).

In an emergency situation, where there may not be time to seek advice or to provide education about consent issues, it is vitally important that staff and indeed carers have correct information. Arscott et al. (1999) explored practical ways to help clinicians assess capacity to consent in a more systematic manner. More recently Tuffrey-Wijne et al. (2005) have reported that staff still have concerns about service users' comprehension and consent issues. Whether this will change, following the introduction of the Mental Capacity Act (2005) and the opportunity for NHS staff to train in this, remains to be seen.

1.7 Waiting times

Waiting times is a potentially contentious issue for any A&E service user. Paine (1994) found that in one UK hospital over 90% of A&E patients were seen for initial assessment within 10 minutes of their arrival and over 83% waited 60 minutes or less, following this, to see a doctor. The NHS plan contains a target that no one should spend longer in A&E than 4 hours. Downing et al. (2004) investigated what factors lead any service user to spend over this time. They concluded that the necessity for admission to a ward was the most significant factor contributing to time spent in A&E. Other factors effecting waiting times included whether or not the patient arrived by ambulance, whether the arrival was during the night and characteristics of the individual. Increasing

age and higher levels of deprivation were associated with longer time spent in A&E. In the study by Piper & West (1998), carers believed that people with learning disabilities were kept waiting for longer periods as compared with non disabled people. If this were fact it might be related to staff attitudes (see 1.2 in this chapter) or staff inexperience (Shanley & Guest 1995) i.e. delaying until they felt they had sufficient time or support from a more confident/experienced colleague. However when interviewing A&E staff Piper (1999) found that service users with learning disabilities were actually more likely to be fast tracked. As this was not made explicit to carers, they made two assumptions: firstly that they were waiting longer and secondly that this was related to the learning disability. If carers' perceptions are incorrect then they themselves need feedback about this. Any waiting period in an urgent situation is likely to seem long. In addition it is notoriously difficult for members of the public to evaluate the equitability of an A&E service that prioritizes people for treatment depending on a range of clinical indicators rather than on a first come first served basis.

2.0 Support

2.1 Support role of carers

Langan et al. (1994) reported that many people with learning disabilities rely on paid and unpaid carers to ensure that their healthcare needs are met. This includes carers needing to be watchful for symptoms of illness, monitor reaction to medication, access services and liaise with health professionals. In a study conducted over a 2 ½ year period within one district Health Authority, Langan et al. (1994) examined the healthcare provided to people with learning disabilities from the service user, carer and GP perspective. They concluded that paid and unpaid carers require support, training, advice and information to be able to fully support service users. They further suggested that unpaid carers should have the opportunity to be supported in their own right and that authorities needed to consider their relationship with unpaid carers. Fox & Wilson (1999) described the experience of 10 sets of parents supporting their adult sons or daughters during hospital inpatient treatment. Carers reported providing high levels of basic care around washing, dressing, feeding, toileting and even on occasions changing bed linen and giving oral medication. Generally nursing staff seemed to appreciate the

input of the carer and it was only on occasions that carers felt staff failed to understand the nature of the service user's disability or disregarded advice. However there was evidence of neglect if the carer was not present e.g. one parent reported that on a previous admission her son had received no food over a period of days as he had been unable to make a menu selection and this had not been noticed by staff. A series of recommendations by Fox & Wilson included listening carefully to carers, agreeing the care plan with carers, providing extra staff if necessary, responding to the service user in an age appropriate way and offering experience with people with learning disabilities as part of nurse training.

2.2 Liaison Nurses/Services

'Valuing People' (Department of Health 2001b) recommends that Health Facilitators be appointed to support people with learning disabilities in all aspects of healthcare. Corbett et al. (2003) suggested that health facilitation is an integral part of caring for anyone with a learning disability but also recommended that skilled workers be employed specifically e.g. to raise disability awareness with mainstream services both at an individual and strategic level. It is recognised that to expect existing learning disability staff to provide this service will dilute other aspects of their work. Jukes & Bollard (2002) described Health Facilitators as needing to work across primary and secondary care, form alliances and promote inclusion.

In addition to the term 'Health Facilitator' which appears to be used both as an overall description of specialist workers across all aspects of health care and as a term referring to those who focus on primary care, the term 'Liaison Nurse' is often used to refer to those specialist nurses working in hospital settings. The use of specialist Learning Disability Liaison Nurses is increasing nationally. Brown & MacArthur (2006) described different support networks developing across the UK: dedicated Learning Disability Liaison Nurses who work across all acute specialities; Community Learning Disability Nurses whose remit includes working within general hospitals and Link Nurse schemes where general nurses from different departments receive additional training in working with people with learning disabilities. Some districts have not employed a single Liaison Nurse but are developing Acute Liaison Services. Some of these services, such as that described by Glasby (2002), focus on preparation of hospital

staff and of people with learning disabilities prior to planned admissions. Liaison Nurses often also have a remit for general staff training.

In 2005 Foster reviewed the literature on Liaison Nurses/Health Facilitators in secondary care. Whilst the studies she reviewed often demonstrated that the role was effective, this effectiveness was measured in different ways in different studies e.g. patient satisfaction, satisfaction of other professionals, clinical improvement, or organizational change. In addition different Liaison Nurses had different roles or combinations of roles including clinical carer, coach (educator), care co-ordinator, communicator and champion. Foster called these the '5 C's'. Many of the studies reviewed by Foster did not involve Liaison Nurses working specifically with people with learning disabilities but with nurses focusing on a specific medical diagnoses e.g. Mental Health, Multiple Sclerosis. Some of these Liaison Nurses were undertaking specialist 'clinical' assessments. For example Sinclair et al. (2006) looked at the role and impact of psychiatric nurses within A&E. The role of the specialist nurse in this setting was to assess the service users for potential mental health problems and to formulate management plans. In the Sinclair study the intervention of a psychiatric nurse had little effect on the service users' satisfaction levels or the length of time which they waited. However this is perhaps unsurprising if their role focuses on assessment as opposed to facilitation. This is different from the role of Liaison Nurses specialising in learning disabilities, as their role is rarely to identify whether a learning disability exists, but is to support the service user, carer and staff. 70% of the general nurses in Slevin & Sines 1996 study felt that a specialist nurse for people with learning disabilities should remain with the service user whilst they are in general hospital, the main reason cited for this being to support communication. There is a need to consider which of Foster's 5 C's a Learning Disability Liaison Nurse is fulfilling, how adequately and whether and how these posts should be developed.

3.0 Carers & Service Users as Research Participants

3.1 Carers as participants

It is common in research which focuses on certain groups within society: the very young; those with dementia; those with learning disabilities, to include the views of

carers as well as, and sometimes instead of, those of service users. The justification for this is that it may be very difficult to access the direct views of certain individuals. In other words where there may be difficulties with communication or understanding of concepts, carers have often been viewed as the best 'advocates' for the service user. Atkinson (1997) and others have described the role of non disabled people in learning disability participatory research. However it is essential to acknowledge that a carer may not share the view of the service user or may have a slightly different perspective. In a qualitative study the themes that are developed from carer transcripts may be different from those that might be generated from verbally able service users. The author believes that there is some legitimacy in including the experiences of carers in trying to understand the issues that face people with learning disabilities. Firstly whilst the focus of carers may be somewhat different to that of service users, in cases where it proves impossible to gain service user views, the carer's perspective may be the only one that approaches the issues from a consumer viewpoint. Carers will be able to raise issues that may be pertinent to service users because of their knowledge of the service user's needs. Particularly in services where access is 'one off' and the service providers are not from a learning disability background, it can be argued that carers are in a better position to advocate for the service users than are the service providers. Secondly a carer's experience of a service may have a direct effect on the service user. For example if the carers are stressed or distressed this might result in tension in the service users themselves, so in some sense the package offered to both will impact on the experience of the service user. It is important to acknowledge that if only carer report is being used, it is not the direct experiences of people with learning disabilities but the experiences of those supporting someone with a learning disability that are being examined.

3.2 Service users as participants

'Valuing People' (Department of Health 2001b) put emphasis on taking into consideration the views of service users. Much of the mainstream work examining the attitudes and views of people with learning disabilities relies on verbal questions and verbal responses. Such an approach automatically excludes those people with learning disabilities who either cannot understand verbal questioning and/or who cannot respond in a recognized language be that oral, written or signed. Direct questioning may also be intimidating for people who do not have good verbal skills and having specific

questions asked, rather than being given the opportunity to talk about issues that are personally relevant, may not engender a feeling of collaboration. Conversely service users might perceive an invitation to narrate their experiences as more threatening, as it requires mental planning to decide what information to share and how to explain this, together with the need to select appropriate vocabulary and grammar in order to be understood. It is therefore important to develop ways of accessing views without relying solely on verbal communication e.g. use of talking mats (Cameron & Murphy 2002). Brown & MacArthur (2006) recommended that a range of methods should be tested and those that proved successful be shared with a wider audience. Couchman (1995) described a study where staff were trained to attend more closely to service users' gaze and body orientation and she confirmed that non verbal service users may be using a variety of communication which goes unrecognized by staff. In addition to paying more attention to body language at the time of an event, other techniques have involved analysing body language whilst using objects of reference and photographic images. Such an approach has been used to determine choices and preferences for non-verbal clients, through the use of 'assessment preference techniques' (Lohrmann-O'Rourke & Browder 1998). These methods have been found to be useful when encouraging non verbal people with disabilities to indicate a preference between people, places, objects etc or to make a choice from a limited number of options. Within focus groups drawings, role play, video and posters have been used to encourage participation from less verbal service users (Goodman 1998). Baker & Hinton (1999) noted that moderators introduced into focus groups to support people with learning disabilities were sometimes seen as authority figures making participants doubt the value of their contributions.

3.3 Service users as evaluators

Supposing that feedback from service users can be obtained, the question then is whether people with learning disabilities can be competent evaluators of a service. Current literature is not in agreement about this. Lowe (1992) described the reluctance of people with a learning disability to be critical about services or providers and Goodman (1998) described the limited understanding of people with learning disabilities about 'complaint systems'. Stenfert Kroese et al. (1998) in a review of literature, concluded that that people with learning disabilities could be informative,

critical and reliable when evaluating residential, day and therapy services. Piper (1998) interviewed verbally able people with learning disabilities and carers, separately, about NHS services and found that, whilst both groups described similar experiences, they tended to rate them differently. People with learning disabilities tended to be less critical. If service user views are to be accessed and used as an indication about the quality of services than it is *vitaly* important to ensure that it is genuinely the quality of service that is being assessed. Services users may be focusing more on appeasing researchers or may be making judgements with a lack of understanding about their rights or with a lower expectation than others. This could artificially boost consumer surveys and lead to healthcare professionals being lulled into believing that equitable services are being provided. In fact there is evidence from the literature that people without learning disabilities can rate themselves as satisfied with services through their low expectations, lack of knowledge of what could be available and a reluctance to complain (Fitzpatrick 1997). As regards evaluation, Faw et al. (1996) have shown that, with teaching, people with learning disabilities can increase their asking, reporting and evaluation skills.

CHAPTER 3

AIMS & RATIONALE

The Introduction has highlighted the Government drivers to change as regards making health services accessible to people with learning disabilities. The Literature Review has indicated the factors that affect this accessibility and has also described how the views of service users with learning disabilities can be gathered directly or via carers. It is apparent from the review of the literature that there is a lack of research focusing on the experience of people with learning disabilities in A&E. This research seeks to redress this and follows an earlier piece of work (Piper & West 1998) in which carers and verbal service users were interviewed about their general experience of NHS services. One of the major issues that arose was that carers felt there was a poor quality service from A&E and linked this to the service users having learning disabilities. The scope of this original investigation was wider than A&E and detailed information was not gathered about A&E from either service users or carers. However in a follow up study (Piper 1999) various professional groups in A&E were interviewed, using a stratified sample, to determine their perception of working with people with learning disabilities.

The aim of this current research was to examine in some depth the experience of people with learning disabilities in A&E. The study was divided into exploring these experiences through interview with the carers; through interview with verbal service users and through non verbal means with less intellectually and verbally able service users. The results from the two earlier studies by the author were used to inform the semi structured part of the interview within this study.

This thesis focuses on the experience of service users with learning disabilities as viewed by their accompanying carers.

CHAPTER 4

METHODOLOGY

1.0 Overview

As stated the main aim of this study was to identify the experiences of people with learning disabilities within A&E. The intention was to use qualitative methods to gain the experiences of both service users and carers. Due to the low number of service users within the sample, who were actually verbally able, the focus of this study is on the qualitative data collected from carers.

Initially the author was also interested in some subsidiary questions for which it was anticipated that some information might be forthcoming. These were:-

- whether the views of people with more severe or profound global learning disabilities could be accessed by using a technique such as that used to determine service user's choices or preferences (as described by Lohrmann-O'Rourke & Browder 1998).
- whether using carers' perspectives is valid in understanding the issues for people with learning disabilities themselves. If there were sufficient participants, the intention was to compare the experiences of pairs of service users and carers both describing the same episode of care. This was to determine whether the same themes emerged and also whether carers and service users would agree on rated levels of satisfaction. This would help inform the debate as to whether people with learning disabilities can be critical evaluators in situations where they may have had only a brief or time limited experience of a service and one where, at the time, they may have felt vulnerable or in pain.
- whether there were differences in participant rating between the two hospitals, given only one had support from local learning disability services.

It was intended to use quantitative data to answer these subsidiary questions but there were insufficient participants, within the timeframe of this study, to allow for such analysis (see Discussion 3.0 Strengths & Limitations).

2.0 Design

2.1 Choice of qualitative approach

This study employed a qualitative design for a number of reasons:

1) The intention was to enable people with learning disabilities and their carers to narrate their experiences. If one explores the issues that face people by using only a series of predetermined questions, this makes the assumption that the topics chosen by the researcher are significant to the participants, whereas they may in fact be less relevant to the participants and more about the researcher's perspectives or interests. In the field of emergency health care and learning disabilities there is too little literature to be clear about what are the significant issues to service users. Whilst literature reviews can provide some insight, they can equally be a hindrance if they constrain the researcher's thinking.

2) Using a qualitative rather than a quantitative approach to some extent helps move away from the debate about the ability of service users to be competent evaluators. If information is being gathered about service users' experiences i.e. if they can narrate their stories, then service users are not being required to make value judgements, although it is acknowledged that their responses will be based on expectation and will also be influenced by the relationship between researcher and participant. Lloyd et al. (1996) have suggested that a process that values service users' experience is less likely to encourage people to adjust to service limitations and more likely to support people to question service provision.

3) Another intention was to avoid imposing a formal structure using the researcher's choice of language, grammar and verbally expressed concepts, as it was reasoned that some of the participants might not be as verbally able and might lack the confidence to express themselves in this way. It was considered that by encouraging participants to 'tell their story', this might enable their voices to emerge. Of interest is that Jonathan Smith (2004) has suggested that the use of the phenomenological approach of IPA not be confined to those who are highly articulate but also be trialled with children and people with learning disabilities. He suggested that the current noninterventionalist stance of IPA interviewing would need to become more interventionist with these

client groups. The author has taken a different approach and made an assumption that reducing the amount of language directed at service user participants might yield richer data. In addition there is evidence from the literature on suggestibility and compliance, that people with learning disabilities are more likely to be influenced by specific questions that a researcher might pose (Gudjonsson & Clare 1995). However in the tradition of many qualitative approaches, after being invited to narrate their experiences more structure was placed on the interview. This was specifically to follow through those issues that participants in an earlier study had identified as raising concerns (Piper & West 1998). Thus after participants had the opportunity to freely narrate their experiences some specific questions were asked.

4) There is evidence from the literature that the use of consumer satisfaction in order to measure people's experience of healthcare has serious flaws (Avis et al. 1997). They concluded that using measures such as patient satisfaction with healthcare has limitations because satisfaction is bound up with other factors such as expectations, autonomy etc. As already described in the literature review some people with learning disabilities have a tendency to be over positive and, if given rating scales, their responses may reflect their desire to please rather than a genuine reflection of their experience. As a result Avis et al. recommended a process that listens to patient narratives.

5) The application and use of qualitative analysis within healthcare settings has been well described by authors such as Holloway (2005) and Smith et al. (1997).

There are two main ways in which to gather data for this type of qualitative analysis - interviews or direct observation. As episodes of care for any individual in A&E are sporadic and unplanned, observations of such events are neither easy to arrange nor record both from a practical and an ethical perspective. Thus it was decided to interview people, with their consent, as soon as possible after their visit to A&E. It is recognized that if information is gathered at different stages throughout a process i.e. during the episode of care, immediately afterwards or some weeks later, then different information might be generated. Visiting people within their homes after they have had time to reflect upon their experiences and attribute their own meaning to these, is capturing information about a person's reflection of an event.

2.2 Choice of Interpretative Phenomenological Analysis (IPA)

The choice of which qualitative approach to adopt was influenced by a number of factors.

1) The emphasis of this research was to allow an exploration of the meanings people attach to their experiences. Thus for this research a phenomenological approach was indicated. Spiegelberg (1959) described phenomenology as deriving from the noun phenomenon, which is defined in the Encarta dictionary as “something experienced: a fact or occurrence that can be observed”. He concluded “that all phenomenology as a study of the phenomena, is subjective in the sense that its objects are subject-related but not in the sense that it makes them completely subject dependent.” (Spiegelberg 1959, p74). Taking a phenomenology stance, each individual’s image of the world around them is dependent on their past experiences, state of mind and belief systems. Creswell (1998) describes phenomenology in terms of “an objective understanding mediated by subjective experience” (Creswell 1998 p86) where that experience is inherent to the event itself. It is this phenomenon that the author sought to gain from the participants. The meaning that people attach to their experiences was considered particularly relevant as previous work by the author had suggested that people’s perceptions of what occurs in A&E and the reality of what happens are not necessarily in accordance (Piper & West 1998). For example carers felt that they had been kept waiting in A&E for a longer time than other people and perceived that this was because they accompanied someone with a learning disability. In actual fact some people with learning disabilities were being fast tracked but this was not made explicit. In a traumatic situation any wait may well seem long to an individual. It is not the wait per se in this situation but the meaning attached this wait that was of significance. This has implications in planning for and improving health care, as direct comparisons between the waiting times of people with learning disabilities with those of the rest of the population accessing A&E would fail to recognize that perceptions can be as relevant to health service users as factual information. Jonathan Smith and colleagues have documented the role of people’s perceptions on their behaviour as regards health matters, in literature on the use of IPA in health psychology e.g. Smith et al. 1997. As regards A&E, it can be argued that

people's perception of how they are treated will effect their subsequent interactions with health professionals and their future use of services.

2) IPA was considered relevant as it acknowledges that the conclusions reached from the information gathered, represents the researcher's interpretation of what the participants mean. This was considered particular important for two reasons. Firstly the researcher had worked for many years as a clinician within learning disabilities and as such would inevitably approach analysis with background experience and personal views. Secondly she had undertaken some earlier research projects in the field of learning disabilities and secondary health care, including within A&E and therefore this particular research experience would mean that previous knowledge would lead to preconceived ideas.

At the beginning of the research, the researcher recorded her expectations of the outcomes of this research, in order that this information could be revisited post-analysis and acknowledged within the findings. Smith (2004) described that IPA should be flexible enough to allow for unanticipated themes to emerge.

3) IPA recognises a double hermeneutic as described by Smith (2004) i.e. the participants' retrospective understanding of the experience which they share with the researcher, coupled with the researcher's interpretation of that recounted experience.

There is an assumption if using a phenomenological approach that there is some shared experience of a group of people. The term 'learning disability' covers a wide range of service users who may not be a homogeneous group. As referenced in the Literature Review, compared with the general population, people with learning disabilities have increased physical health problems, higher levels of mental health issues, an increased likelihood of having physical disabilities and often experience difficulties in communicating in a way that hospital staff can understand. Any of these factors or interrelation between these could influence people's needs and experiences and may impact more than the actual intellectual disability. A&E nurses have identified communication rather than intellectual disabilities as a significant issue for them with this group of service users (Sowney & Barr 2007, Piper 1999). This study sought to identify whether there are shared issues for people with learning disabilities or their carers when accessing emergency health care. It is acknowledged that identified issues

may be common to any individual visiting A&E with or without an intellectual disability. There are implications for the organisation if there are shared experiences and common areas of difficulties, as such findings could be incorporated into access strategies of mainstream hospital services.

The part of the research described within this thesis focuses on the question about the meanings carers of people with learning disabilities attach to the A&E experience. The views of verbal service users and non verbal service users have not been reported within this thesis. This is because of the small number of these participants involved; two verbal and three non verbal service users.

2.3 Other data collection

In addition to the qualitative interviews some quantitative data was collected in the form of Likert Ratings Scales. It has already been established that the use of rating scales to measure satisfaction with healthcare has its limitations (Avis et al. 1997). However the rating scales were not to evaluate the service per se but served a number of purposes:-

- 1) to allow for a comparison between what participants were saying and ratings of ‘apparent’ satisfaction. A great deal has been written about the misinterpretation of satisfaction rating scales and the tendency of participants to appear falsely positive. It felt important to get an overview to balance what was being said i.e. if specific questions are asked the answers might be affirmative, but it does not necessarily mean to say that the participant is satisfied with this and vice versa. For example if a participant indicated that no communication aids were used one might draw a conclusion that this was not helpful – however this might be a false assumption if the service user did not need any specific communication aids.
- 2) to help the researcher be clear as to the participant’s value systems or beliefs. For example a participant might say that no attempt was made to gain consent and then go on to say that they were very satisfied with how consent was managed.
- 3) to allow for a quantitative comparison between service user and carer participants who may raise different issues within the qualitative analysis but may have a similar or indeed dissimilar perceptions as regards the areas covered by specific questions.

4) to allow for comparison between participants from the 2 hospitals involved in the study.

The rating scales were embedded within the format of the interview (see Interview Schedule in Appendix 5). The scores for overall satisfaction have been included within the Participant Information (Table 1) as part of the general background information.

3.0 Setting

The study was conducted at two A&E departments situated in the same region of the UK. These departments are part of general hospitals approximately a hundred miles apart in two different NHS Trusts. There are a number of similarities between the areas being served, including that they have significant rural catchments and high levels of seasonal visitors - which can boost the population figures by almost double at certain times of the year. They differ primarily in that Service X is serving a smaller community spread across a smaller geographical area. Service Y covers a considerably larger geographical area and has a larger population to serve.

Service X is part of an NHS community that has one General and 10 Community hospitals, which provide acute medical and surgical services to 270,000 permanent residents, plus seasonal visitors, living in an area covering 300 square miles. The A&E department involved within the study is the only one within the Trust and is based at the General Hospital. It provides 24-hour emergency services for adults and children. There are 10 minor injury units situated at the 10 community hospitals. The number of people treated by this A&E per year (as reported by the hospital) is approximately 73,000. Service X has had the same Learning Disability Liaison Nurse in post since the job was first created in 2002. She is part time and based within the hospital - operating predominantly from 9a.m.-5p.m. Her remit is to work with any ward or department including A&E to support the treatment of people with learning disabilities.

Service Y is part of an NHS community that has one General and 16 smaller hospitals which provide acute medical and surgical services. There are over 500,000 permanent residents within the county boundaries, plus seasonal visitors, living in an area covering

1376 square miles. However some of these residents will travel to a neighbouring county to access their nearest A&E. Thus the acute Trust serves a population of approximately 400,000. The A&E department involved within this study which is the only one in the Trust, is based at the General Hospital and offers 24-hour emergency services for adults and children. The smaller hospitals run one casualty (nurse led) and 8 minor injury units. The combined number of people treated per year at A&E and Casualty is in excess of 60,000, which is fewer than within Service X but is the reported figure from the hospital. Service Y had no Liaison Nurse post.

4.0 Participants and Recruitment

4.1 Inclusion criteria

All carers of people with a learning disability, accessing the A&E departments of both services within an 18 month period, were eligible to participate in the research. The intention was to interview as many participants as possible within the time frame in order to maximise the chance that quantitative analysis might also be included as well as the main analytic qualitative methods. A&E staff were asked to give information about the research to carers or people with learning disabilities on their discharge to home or to a ward. The only exceptions were following a fatality or a very serious life threatening trauma, in the latter circumstance A&E staff were to exercise their discretion as to whether it would be appropriate.

Sometimes it is not clear to staff if a service user has a learning disability as oppose to another diagnosis. This tends to be the case for more able or verbal clients, some of whom might attend A&E on their own. In order to maximise the chances of offering the research interview to all potential participants, notices were placed within A&E inviting carers/service users to identify themselves. These notices were only accessible to carers and service users who were able to read and were simply there to ensure that those, not recognized by staff as having learning disabilities, were not excluded from the study.

Service X has a system, introduced during prior research by the author, to identify service users who are already known to the Community Learning Disability Teams. If

people did not respond to the first information letter or A&E staff omitted to hand out the information, then an identical letter was sent to the home address in those cases where it could be established that a person with learning disabilities had visited A&E. No response to this would be interpreted as not wishing to take part. Service Y has no such system to identify if a person accessing A&E has a learning disability. Neither Service X nor Y records the numbers of people with learning disabilities whom they treat.

Initially there was a low response rate to the study and strenuous efforts were made to increase recruitment e.g. alerting local services (such as special schools, carers' support groups and local residential provision) about the research. In addition telephone calls and unannounced visits were made to A&E to check whether front-line staff were aware of the research and were distributing information packs. The author also gave a presentation about the research to the Patient and Public Information Group, which prompted the group to write formally to one Trust with a request that the work be supported by senior management.

It was the overall experiences of the group who are encompassed within the term 'learning disabilities' that was considered most relevant in this research. It is recognised that the term 'learning disability' covers a wide range of ability levels and may include people with additional health problems and/or physical disabilities. No attempt was made to select participants from different service user groups (e.g. child and adult, verbal and non-verbal, mild or severe learning disability). Instead the demographics of the participants have been considered but no inferences can be made about this. Nor were attempts made to match the service users across the two service areas. There were too few within the study to do that and there was no reason to suppose that both services would not be serving a similar population as regards learning disabilities.

4.2 Potential participants

As there were no figures in either hospital for the number of people with learning disabilities who use A&E, it was hard to anticipate how many potential participants there might be in the timeframe of the study. In all, 13 carers came forward (8 from one hospital and 5 from the other), together with 5 service users. Interestingly none of these reported having been given information by A&E staff at discharge. Most participants

responding from Service X had been sent the information at home after visiting A&E. In Service Y, 4 of the 6 respondents had heard of the study through local networks, 1 saw the notice in A&E and requested information from staff and 1 person was retrospectively offered the opportunity to take part by staff after she raised some concerns about the service. The study was dependent upon people with learning disabilities using A&E; their willingness and ability to take part; staff within A&E recognizing the presence of a learning disability and then remembering to hand out an envelope containing information about the research.

4.3 Exclusion Criteria

If participants were previously known to the researcher in her clinical capacity a psychology assistant conducted the interview. This was to guard against the possibility that the researcher, as a Community Learning Disability Team member, might have had some involvement in a participant's A&E experience. As part of quality control the assistant accompanied the researcher to observe before interviewing. The data from any participant, where the assistant was present at the interview, was not included in this thesis. However all information gathered was included in the feedback report to the hospitals, so that all contributors had the opportunity for their voices to be heard.

4.4 Participant Information

The participants in this thesis were 11 carers - 6 family carers and 5 paid staff. Of the family carers interviewed, there were 3 mothers and fathers who attended A&E together and were interviewed together; 1 mother who attended with a partner but was interviewed on her own; 1 mother who was a single carer and 1 sister. Of the 5 paid carers, 3 were working in NHS residential services; 1 in a private residential home and 1 in a Local Authority respite service. One of the 11 carers was accompanying someone of 14 years old, the remaining service users were 17 or older. 6 of the service users were male and 5 female.

All participants were known to the local Learning Disability Services who were using an IQ of below 70 as one criterion for entry into the service. So although the service users were not cognitively assessed for the purpose of this research, it can be assumed that the level of cognitive and/or social impairment was sufficient for a diagnosis of

learning disability. Carers all described learning disabilities that required some form of support: 1 of the service users lived semi-independently, the remainder all had 24-hour care. A number of service users had a dual diagnosis e.g. learning disability and hearing impairment; learning disability, schizophrenia and autism. Learning disability was the only diagnosis common to all, but several service users had epilepsy and several had a diagnosis of an autistic spectrum disorder. Some carers made reference to a specific condition e.g. Tubercular Sclerosis, Down's Syndrome.

Table 1 gives information about the carers who were included in this study (and the service user they accompanied). This includes if carers were post-60 years old (recorded as older adults) and some indications of their overall impression (by rating) of A&E. Information about the service users they were accompanying includes whether the service user was a child/adolescent (under 16), between 17 - 21 years (young adult) or above 21 (adult); an indication of the degree of learning disability and other diagnoses as described by the carer; the amount of living support required; some information about the service user's communication skills based on carer's report or researcher's observation; the reason for admission and the outcome in terms of whether treated and discharged or admitted. Whilst service users' levels of understanding were variable, all had some impairment in understanding and some limitations with language.

Table 1: Participant and Service User Details

Participant (Carer) detail			Service User detail		
Relationship to service user	Living arrangements	Overall Satisfaction Rating with A&E	Gender & Age range	Diagnosis/Ability –as described by carer	Mode of arrival, Reason for A&E visit and Outcome
1. Single Mother Older adult	Lives separately from service user but provides main support to him in his semi supported living setting	Fairly satisfied	Adult male	Mild learning disabilities, hearing impairment. Communication appears good but can't understand words such as 'allergic', can't read, but able to work with some support.	Arrived by ambulance Alcoholic poisoning Admitted
2. Mother & Father Older adults	Live with service user who requires 24 hour support	Very satisfied	Adult male	Down's Syndrome, moderate learning disabilities. Understanding of language impaired, communicates verbally but communication affected by pain.	Arrived by ambulance Lung infection Admitted
3. Mother & Father Older adults	Live close to residential home where service user resides with 24 hour support	Very satisfied	Young adult female	Severe learning disabilities. Some verbal ability, but maybe out of context, can understand simple instructions, unable to describe symptoms or feelings.	Driven by carers Broken fingers Discharged after treatment
4. Professional carer, female	Support worker from private residential unit where service user lives with 24 hour support	Not very satisfied	Adult male	Moderate learning disabilities, autism & schizophrenia. Good understanding, can communicate -able to understand procedures but not concept of waiting.	Arrived by ambulance Dislocated ankle Discharged after treatment

Participant (Carer) detail			Service User detail		
Relationship to service user	Living arrangements	Overall Satisfaction Rating with A&E	Gender & Age range	Diagnosis/Ability --as described by carer	Mode of arrival, Reason for A&E visit and Outcome
5. Sister	Lives in separate home from service user, who lives with parents with 24 hour support.	Fairly satisfied	Adult female	Moderate/ severe learning disabilities. Can verbally communicate and answer basic questions.	Arrived by ambulance Stomach pains and severe eating problems Admitted
6. Mother & Father	Live with service user who requires 24 hour support.	Very satisfied	Young adult female	Moderate learning disabilities. Can talk but has speech problems- speaks fast and leave off the ends of words or runs all words into one. She can tell others what is going on.	Driven by carers Broken nose and injuries to forehead Admitted
7. Professional carer, female	Manager of respite unit where service user receives regular respite. Service user requires 24 hour support.	Not very satisfied	Adult male	Moderate learning disabilities. Has very limited understanding and is quite repetitive but with support can understand verbal conversation and can communicate.	Arrived by ambulance Going into status & urinary tract infection. Discharged with medication after treatment

Participant (Carer) detail			Service User detail		
Relationship to service user	Living arrangements	Overall Satisfaction Rating with A&E	Gender & Age range	Diagnosis/Ability –level of ability as described by carer	Mode of arrival, Reason for A&E visit and Outcome
8. Professional carer, male	Manager of NHS residential home where service user lives with 24 hour support.	Fairly satisfied	Adult female	Down's Syndrome, dementia, hearing loss and some visual impairment. Limited verbal communication and understanding.	Arrived by ambulance Sudden severe physical symptoms Discharged after observations/monitoring
9. Professional carer, female	Support worker from the NHS residential home where service users lives with 24 hour support.	Very satisfied	Adult male	Non specified learning disabilities. Verbal communication and some understanding, tendency to echolalia.	Driven by carers Injury to arm - swelling and pain Discharged after treatment
10. Mother	Lives with service user who requires 24 hour support.	Very satisfied	Adolescent male	Within special school for children moderate to severe learning disabilities. Autistic Spectrum disorder	Arrived by ambulance Severe epileptic seizure Discharged after treatment
11. Professional carer female	Support worker from the NHS residential home where service users lives with 24 hour support.	Not at all satisfied	Adult female	Non specified severe learning disabilities. Very limited verbal skills, some understanding.	Ambulance attended but service user anxious therefore driven by carer Epileptic seizure resulting in fall and wound to head Admitted next day

5.0 Measures

It is common within IPA to use a flexible interview schedule. In this research firstly participants were invited to recount the story of their A&E experience (Appendix 5, Part 1). Structure was imposed by asking the participant to recount the event chronologically. This approach was adopted to allow participants the opportunity to focus on those factors that were pertinent to them. Initially they were asked to describe their journey through A&E from the time of arrival to the time of leaving. Describing their journey allows a natural flow enabling the participant to think through events chronologically which is both a logical approach and one which mirrors the way in which people often recount events. If there was a burning issue from an individual and they broke off from the chronology to focus on this, this was encouraged and only when that specific recollection came to an end would they be taken back to a previous point, “earlier you told me how you went into a cubicle after seeing the triage nurse, tell me about this”. Sometimes specific questions were asked in order to clarify what the participant meant. Specific questions might also be used if the participant came to a stop in describing what had happened e.g. if a participant were to say that she had been “seen by a triage nurse and then asked to wait”. There was a deliberate choice not to simply ask, “and what happened next?” as the participants may have responded by describing the next dynamic event e.g. “and then we saw a doctor”. Under these circumstances the fact that the participant may have waited and what they experienced during this period might be lost information, so the researcher used prompts such as “did you go back to the waiting room?” Use of prompts draws out more information but also means that it is more difficult to determine which factors were salient to the participant i.e. which would have been mentioned if not prompted.

The second part of the interview focused on specific questions about different areas of the A&E experience (see Appendix 5, Part 2). These questions were developed as a result of the earlier research by the author (Piper & West 1998) and explored issues that had been raised by verbal service users, carers and A&E staff. The A&E staff themselves commented on the interview schedule, in order that the researcher might be sure that the questions were meaningful e.g. A&E suggested that rather than just ask

about overall waiting experience, it might also be helpful to consider how soon a patient was assessed by triage. The specific areas upon which participants were questioned were: Communication, Consent to treatment, Pain management and Waiting times. At the end of the questions on each of these sections the participants were required to rate their level of satisfaction on a 4 point Likert scale as previously discussed in 2.3 of this chapter.

In order to use the rating scales in a quantitative way specific numbers of participants were required. For example calculations of power coefficients suggested a statistical comparison between the two hospitals would require 40 participants from each site. Neither hospital kept records of the numbers of people with learning disabilities using their service thus it was unclear before the start of the research as to how many potential participants there might be. In the event there were too few participants within the time frame of this thesis to report on any of the quantitative data.

6.0 Procedure

The research was approved by the appropriate NHS Ethics Committee (Appendix 1) and the four Research & Development departments that covered the Acute and the Community Services in the two districts.

Prior to beginning the research the author had discussions with both A&E departments via the Nurse Manager at one site and the Nurse Manager and Lead Consultant at the other, to gain their consent and support for the study. Some Senior Managers within the hospitals were also involved.

Agreement was obtained for support, if required, from the Community Psychology Services in the two districts. This was to ensure that any concerns that might be raised during the interview about the wellbeing of service user or carer, whether related or not to the A&E experience, could be addressed.

A&E staff undertook to give out information to carers and service users on discharge from A&E. This information was in an A4 envelope and consisted of a brief introduction to the research and a consent 'to be contacted by the researcher' slip which

could be filled in at the time or sent back to the researcher in the stamped addressed envelope included (Appendix 2). This introductory information, provided in word and pictorial form, offered people the opportunity to take part in the study. (Appendix 3).

On receiving a telephone call or a reply slip from a potential participant, the individual was immediately contacted for an interview. A mutually convenient time and meeting place was arranged (which in the case of all participants was the family or residential home of the service user or carer).

The researcher then visited the participant at the prearranged time and conducted the interview.

The interview format is shown in Appendix 5. After introducing herself the author made sure that the information about the study had been received, read and understood by the participant. Participants were reminded about the reasons for the research and what would be done with the results. They were assured of individual anonymity and that nothing they discussed would negatively affect the service offered to them in the future. They were also asked if they were willing for the interview to be recorded on a digital Dictaphone. (One participant asked for a copy of her transcript which was duly sent to her.) Participants were invited to ask any questions about the research. They were then asked to sign a consent form, the design of which was influenced by the NHS ethics committee (Appendix 4). Prior to commencement, the structure that the interview was to take was explained and participants were reminded that they could stop the interview at any time if they so wished.

After these formalities the interview proceeded according to the format. The interview consisted of two parts as described within this chapter, section 5.0.

Each interview was recorded on a Dictaphone and in addition the responses to the specific questions in part 2 were also recorded on a prepared agenda to ensure that the probe questions had all been covered. For example participants were asked whether the service user could understand what A&E staff were saying to them –after the answer had been given, if the following had not been covered, participants were then specifically asked about the potential communication aids that might have been used and various types were listed as prompts.

The author attended each interview with leaflets about the local Patient Advisory Link Service (PALS) and the relevant Trust's Complaints procedure – should these be required.

At the end of the interview participants were invited to raise any further issues. These were sometimes not related to the research study, but nevertheless required some action on behalf of the researcher. There were some requests to provide information not directly related to A&E (e.g. Department of Health information on the Mental Health Capacity Act to a participant interested in consent) or to facilitate the provision of a service (e.g. make a referral to Community Adult Learning Disability Team, on a participant's behalf).

7.0 Researcher

There was one researcher, a Consultant Clinical Psychologist with a background of working within NHS Learning Disability services. She had previously been involved in research with people with learning disabilities using hospital services. The potential effects of her past experiences and current interests, on the experimental design and the subsequent interpretation of the results, are considered in the Discussion (2.0 Reflexive Analysis and 3.0 Strengths & Limitations).

During the course of the project two psychology assistants were involved. Both were working primarily as clinicians with the Consultant but were also interested in the broader functions of the psychology department. As regards their input one was solely involved in practical and administrative support before the study started, which included sourcing and costing up the equipment required. The other was more active during the course of the project, including interviewing when the participant was known to the researcher and presenting information to non verbal service users for the part of the research that was involved in gathering service user opinion. For the purposes of this thesis any data gathered by or when the psychology assistant was present, has not been included within the analysis (see 3.3 in this chapter).

All data was analysed by the researcher herself.

8.0 Analysis of transcripts

Within this thesis a total of eleven carer transcripts were analysed. Each transcript was the result of an interview that lasted between 45 minutes to 2 ½ hours. The transcripts were typed up verbatim and then analysed.

Brocki and Wearden (2006) reviewed in excess of 50 published articles using IPA within the field of health psychology. It is clear from this review that the exact methods that researchers are using to analyse data can differ. Larkin et al. (2006) also describes how papers describing the analytical steps show “considerable flexibility and variation with regard to the available routes through this process” (Larkin et al 2006 p104). Jonathan Smith who has developed the IPA approach focuses on the discovery of themes and connections from within the text itself as oppose to drawing on past literature or theory at the early stage of analysis. This thesis has used the guidelines as described by Smith et al. (1999), Smith & Osborn (2003) and Smith (2004) in the process of analysis.

According to Smith (2004) IPA is idiographic and analysis begins with the detailed examination of one case until some degree of ‘closure’ has been achieved, then the detailed examination of the second and so on. Only when this has been undertaken should cross case analysis proceed.

Initially attempts were made to use a computer program to aid with categorising the data, but the researcher found this more challenging than manual analysis. Lonkila (1995) cautioned, that whilst programmes such as ATLAS/ti (usually employed with grounded theory) can be adapted to interpret other data, when used by a novice qualitative researcher the techniques available with such a programme may steer the analysis towards one theoretical model.

Smith & Osborn (2003) describe analysis as a 5 stage process and the author has used these stages to guide her analysis.

Stage 1: Each transcript in this study was read and reread before points made by the participant that seemed pertinent were noted.

Stage 2: Each point was then revisited together with the transcript, to help maintain context, and the author’s interpretation was made. Two examples of this initial process are shown in Table 2 below:

Table 2: Examples of searching for emerging themes from the original transcripts

Notes on text	Text	Potential Interpretation
Example 1 (Participant 11)		
Carer repeating advice – use of ‘again’	<i>I also stressed again that, “if you are going to do something she must have Midazolam or some sort of sedation” and then that was about it.</i>	Not feeling listened to Carer perceives self as expert re SU
Staff seeking advice/ support from own service	<i>She then went off, she looked at Kelly. She then sort of made a phone call, come back again,</i>	Staff lacking confidence ?relating to lack of LD experience
Carer asking or/demanding information	<i>and I said to her, “Well, you know, what are you going to do?”</i>	Carer asserting self -trying to get answers – ‘in the dark’
Carer stressing the advice she had already given	<i>So I said “Well you aren’t going to be able to do anything unless you give her some sort of sedation”</i>	Carer as ‘expert’ re SU
Carer not speaking of staff in positive way - dismissive	<i>She mentioned a doctor’s name, he was somewhere doing something. I don’t know, he was tied up with something and, I can’t remember his name. So she said can I have a look at it can I try and put some of those little fairies.</i>	Carer lacks confidence in staff competence/ experience in relation to LD
Carer ‘giving permission’ with ultimatum and warning	Researcher: Fairies? <i>Yes, that right. I said, “Well Kelly won’t let you go near her but you can have one attempt at it”. So she just went to go near Kelly but Kelly hit out, that was it.</i>	Carer not listened to ?Carer feeling vindicated
Lack of introductions	Researcher: Was that the doctor? <i>Yeh she went to hit the doctor, yes, well I assume it was the doctor that she hit because she didn’t introduce herself so I suppose it was a doctor I think it was a doctor.</i>	Absence of relationship/emotional link between carer and staff

Example 2 (Participant 2)		
	Researcher: in terms of communication, how we could make that any better?	
Long periods of waiting Little to occupy	Father: <i>Only, perhaps when you are just hanging about, hanging about, the time does drags so and you have nothing to do but sit there and look at each other, that sort of thing.</i>	
Staff busy	<i>I think perhaps occasionally you have to accept that they are very busy but occasionally if they could just pop by and say everything's going all right, sorry about the delay but otherwise -you know that sort of thing.</i>	Justification by carers (for wait)
Carer's wants some acknowledgement of wait and some feedback	<i>But you have to relate that to how busy they are.</i>	Feedback during wait & acknowledgement important to carers
Apology helps Refers to Consultant by first name	Mother: <i>But Duncan did apologise when he came along.</i> Father: <i>Yes he did.</i>	Empathy by carers with staff
Recognition of issues for staff	Mother: <i>For how long we'd been waiting. There was ever so much going on. How they cope I do not know.</i>	Relationship/ emotional link between carer and staff
		Empathy with staff

Stage 3: The emerging themes were listed separately and connections made between them. Initially there were in excess of 20 emerging themes:- these included issues of support, barriers to accessing service, carer as expert, waiting, communication, consent, being or not being listened to etc. Whilst some of the categories were very obviously related and could be merged there remained a number of distinct emerging themes. The author then placed all the quotes that seemed relevant to each of these themes under the relevant heading. She then reviewed the information in each emerging theme – using the transcripts once again for context. Thus the emerging theme of Waiting was reviewed. Whilst the quotations within this theme made reference to waiting the author attempted to explore the meaning behind the participants' comments. For example the following-

being given explanations as to why you wait that amount of time. And just people saying "Is there anything we can do to make it comfortable for you" because she might become distressed by having to wait. And just checking whether someone is too cold, they might need some extra blankets while they are sat there, instead of having to seek them out (P5 343)

suggests that being given some feedback during this waiting process would make a difference. In addition to this, the carer was implying that some nurturing or ‘caring’ from the staff would help, as would recognition of the service user’s potential difficulties (i.e. might become distressed) and therefore those of the carer. Another quote raised similar issues about receiving feedback-

you have to accept that they are very busy but occasionally if they could just pop by and say “Everything’s going all right, sorry about the delay” But you have to relate that to how busy they are. (P2 170)

but also demonstrates that carers have some understanding or empathy towards the staff, recognising that the A&E department is very busy. These concepts were followed through by other carers-

We assumed OK, they are working on other people, but it would be nice if you had some indication. I think we would all wait with a better grace if you knew the reasons. (P3 711)

In this way the author reviewed the participants’ comments using a more interpretative approach. Thus the original emerging themes were either refined or changed to a group of connecting themes. These Connecting Themes were:-

Carer as expert, which included concepts such as being listened to; collaborative relationships between staff, carers and Liaison Nurse

Communication including being kept informed, communicating pain, communication between service user and others, communication between staff and carers, communication between staff, effects of pain or trauma on communication and what facilitates and improves communication

Empathy and Understanding shown towards service users, staff and carers

Care and Caring there were factors relating to medical care (treatment and pain management), basic care needs and those associated with nurturing care.

Compliance and Consent how to determine, factors that affect this and attitudes towards

Support Network including the role of service users, carers, staff and the Liaison Nurse within this process

Responsibilities and Empowerment – this included carers’ responsibilities to the service users and also to others for whom they may care, staff responsibilities, perceived abdication of responsibilities and the balance between participants feeling in control or powerless

The emerging theme of Waiting no longer existed as the author interpreted the meanings of the participants’ comments to be about being kept informed (Communication); nurturing (Care & Caring) and empathy (Empathy and Understanding)

Stage 4: There still existed relationships between the Themes and some degree of overlap and the author sought to identify the over arching connections between these – i.e. the development of super-ordinate or master themes. The questions that the author was now asking were for example ‘What does it mean to the participant to be listened to?’, ‘What is the purpose of the participant commenting on whether the service user is communicated with?’ In the latter example a number of participants said that the service user either did not understand or the nature of the injury or its treatment rendered the service user less communicative – yet carers still felt that an attempt by the staff to communicate with the service users was important.

I don't think Sharon would care one way or the other quite frankly. But I think it's nice that they do talk to her. She is the patient. I think it's nice that they try to talk to her and try to communicate with her. (P3 234)

They started off trying to communicate with Julie, which was really nice to see because in most cases people will just talk straight to the carer. But I think obviously with the difficulties that Julie can't hear particularly well and her sight is impaired ... (P8 74)

The author’s interpretation was that the participants were expressing that they wished the service users to be valued and that communicating directly with somebody is valuing. Similarly being listened to implies that what you say is of value so again there was an interpretation made that the participants were referring to being valued in themselves (in this case as experts relating to the service users they were accompanying). Thus a master theme of ‘Interactions that are Valuing’ was developed.

Participants' references to being nurtured have already been used as an example within this text – nurturing could be seen as sense of being valued but re-examining the transcripts suggested that these acts of nurturing were above and beyond valuing and involved some sense of Emotional Responsiveness or Connexion.

This could be between different parties e.g. staff and service user:-

The client was obviously taken with him [the doctor] because he leaned forward and put his arms around him. The doctor responded. It was lovely, really nice. (P9 87)

or carer and staff

I think they are terrified of traumatising her really and she can throw herself around a room quite violently I feel for them. They do their best. (P3 274)

A number of the themes identified could be encompassed by this concept and thus Emotional Responsiveness was also seen as a master theme.

Stage 5: When the author had identified potential master themes each transcript was then revisited to see if it was valid to use these master themes to interpret the meanings behind the participants' original comments. A matrix was also drawn up to identify which of the transcripts contained information considered relevant to the chosen master themes and it was of interest that each theme appeared in all eleven of the transcripts. The quotes that were relevant to each theme were noted and marked.

Table 3 demonstrates the overall process described above, for one quote from the text.

Table 3: the development from initial to master theme

Initial Text	Initial theme	Connecting theme	Final theme	Master
<i>I also stressed again that, "if you are going to do something she must have Midazolam"</i>	Not being listened to	Carer as expert advisor	Listening to carer advice	Interactions that are valuing

CHAPTER 5

RESULTS

Five master themes were identified from the analysis. Table 4 lists these master themes and the sub themes associated with each.

Table 4: Master and sub themes

MASTER THEMES	SUB THEMES
Interactions that are valuing	Involving the Service Users Listening to carer/ liaison nurse advice Empowerment vs powerlessness Keeping carers informed (introductions, feeding back)
Emotional responsiveness	Nurturing (caring) Empathy & Understanding Recognition
Support	Carer to service user & staff Equipment Liaison Nurse
Compliance	Compliance & Consent
Responsibilities	Risk taking & management Medical care including pain issues

1.0 Interactions that are valuing

Many of the comments made by participants suggested that one of the most significant factors is whether A&E staff were valuing of service users and their carers. This might be portrayed in a number of ways.

1.1 Involving the service users

How positively participants viewed A&E was linked to whether participants perceived that service users were treated with respect and involved in the process of their own treatment/care. If participants perceived the service user to be valued they clearly appreciated this. A&E staff who attempted to communicate directly with the service users were seen more positively, even when the service user's communication was limited

They started off trying to communicate with Julie, which was really nice to see because in most cases people will just talk straight to the carer..... they were doing their best to communicate with Julie. It was nice. (P8 74)

or the service user may not have been concerned or aware of this effort.

I don't think Sharon would care one way or the other quite frankly. But I think it's nice that they do talk to her. She is the patient. I think it's nice that they try to talk and try to communicate with her (P3 234)

A&E staff might be aware of difficulties in communicating with the service user but would nevertheless continue to try direct communication first. Most carers felt that staff relied on them to help with communication which they felt was sensible

If he either didn't quite understand the question or wasn't quite sure then they looked to us (P2 90)

If staff did not always communicate with the service user the carer often felt that there was a good reason for this

possibly he talked less to her [service user] because he could see what was going on because he said "I don't want to distress her anymore than she is distressed already" (P3 240)

Researcher: *Who did the staff communicate with - with you, with Jez and you or just with Jez?*

Um, I would say both of us, but mainly, both of us first, but then when they sedated him they couldn't really talk to him so it was generally with me. (P4 91)

From participant report staff relied heavily on verbal communication when trying to involve service users. A few participants described that staff used more simplified language at times but very little in the way of specific aids were used. None of the staff used any sign language, however none of the carers of this particular group of service users felt that this would have been useful. No photo cards or pictures of equipment or procedures were used in any of the cases. Staff did use some gesturing but, according to participants, no more than they would in normal conversation and only on a few occasions were demonstrations used by staff.

Joe has this Piglet, you know from Winnie the Pooh, and we took the Piglet character into hospital with us and they put the pulse meter on Piglet to show Joe what was going to happen (P10 77)

One participant talked about how staff made an effort to stand directly in front of a service user with partial hearing and visual impairment in order to aid communication and another commented that staff were good at using clear facial expressions as part of their communication.

Several carers mentioned that the Liaison Nurse either at the time or on previous occasions made more use of demonstrations and aids, such as pictorial calendars, than did the rest of the staff.

Whilst participants thought that communicating directly with the service user was more valuing they did not necessarily feel that this was related to staff attitudes. Confidence could also play a role in the way in which staff communicated with service users

Some staff are less confident.....I would say that the nurses are probably more confident. On the whole, within the ward, the most confident would be the cleaners.

Researcher: *So who would you identify as less confident within A&E?*

Probably the doctors (P5 115)

Only 2 of the 11 participants described insufficient communication with the service users which the participants viewed as non valuing. One, talking about her experience of the hospital in general, commented

I think they talk about Kate in front of her, rather than involving her in the conversation if I'm there I usually turn it around and then get them to involve her (P5 144)

Another, accompanying a person with quite severe learning disabilities, reported that staff spoke only with her the carer and made “no attempt” at verbal communication with the service user. She commented that she the carer,

would prefer them to speak with Kelly because I can answer with Kelly..... I can interact with them with Kelly (P11 254)

However she said that she did not know whether the service user herself would have wanted direct communication. It may be of note that this service user and carer had an exceptionally long wait, which was apparently a result of there having been a major trauma during the afternoon to which the staff were attending. If staff were extremely busy and the service user had been waiting for a very long time, they may have tried to speed their assessment at the expense of time given to communication. This is not an excuse but may be an explanation.

One participant stressed that staff did speak directly with the service user as well as the carer, but she felt that not enough time was given when staff were trying to communicate. In her opinion this was because staff were extremely busy at that particular time, knew that the service user was accompanied by a professional carer and hence did not set aside more time. All other participants did feel that sufficient time was given for communication, although they might have had to explain the need for this first.

once I had explained, they slowed things down and the doctors waited for him to think about things and answer (P10 80)

Several participants talked about the importance of specific training for staff so that they were more confident in involving service users with communication difficulties. A participant from the hospital with no Liaison Nurse said,

What would be an idea would be if they had a member of staff appointed to that hospital who was able to go into whatever ward to communicate with anyone who had communication difficulty. (P8 138)

One carer, a learning disability nurse herself, wondered how amenable medical staff would be to receiving such training but felt it needed to be for all staff.

I think it needs to be at all levels, particularly doctors that are explaining the process and what is happening and asking questions (P5 263)

She further went on to suggest that service users themselves might provide a valuable source of training, as

there are groups of service users ready to carry out training (P5 269)

Participants also felt that it was important for staff to explain the treatment to service users

He [the doctor] explained everything he was going to do, if he was going to move an arm or why he was moving it and asked various questions some of which Les could answer but if not we helped (P9 67)

1.2 Listening to carer/ Liaison Nurse advice

Commonly carers talked of the importance of being listened to. They clearly felt that they had some expertise or knowledge relating to the service user they accompanied and wanted this to be recognised and acted upon.

They didn't understand ASD but, once I explained, that was fine with the doctors (P10 22)

they did take advice as to what I thought would be appropriate (P8 234)

If carers did not feel listened to, which proved to be the minority, they became frustrated particularly if they felt that they had to repeat advice

When I went to the receptionist I did say "if we need to do anything with this lady we usually put in place Midazolam". When she [triage nurse] finally came out I then said, "Look before we even start she will need some sort of sedation"..... Anyway, getting back to the doctor. Again I then had to repeat all Kelly's history, all her medications I also stressed again that "if you are going to do something she must have Midazolam or some sort of sedation". (P11 56)

This carer's perception was that no-one was listening to her advice and when the doctor decided to try and examine the service user without any sedation in place, there was almost a feeling from the carer that she was vindicated when the service user lashed out.

I said "Well Kelly won't let you go near her but you can have one attempt at it". So she just went to go near Kelly but Kelly hit out, that was it. (P11 102)

Significantly when carers felt that they had not been listened to, this effected their entire perception of the competence of the staff. For example in the case above the fact that the doctor sought advice from a colleague was recalled in a negative way and perhaps suggested that the doctor was less competent

She then went off... .. She then sort of made a phone call, come back again, and I said to her "Well, you know, what are you going to do?". (P11 91)

whereas carers who felt more involved in the process did not use the same type of language if staff sought advice from another member of staff.

We saw the A&E doctor he wanted more advice and wasn't totally clear, Duncan Somebody or whatever and he was, um, charm itself. (P2 29)

Whether or not the carers felt listened to, there was a consistent belief from those visiting the hospital, that employed a Liaison Nurse, that A&E staff listened to and valued the Liaison Nurse's advice, as they acted upon it (see 3.3 in this chapter).

1.3 Empowerment vs powerlessness

Those who felt that staff not only sought their advice, but actually worked in collaboration with them, seemed to feel empowered. This sense of empowerment sometimes came from what carers saw as joint decision making. A number of carers used the term 'we' suggesting a process of collaboration.

I was able to talk through with a doctor what we felt we should give her and what we shouldn't. We did discuss the possibility of giving her some diazepam (P8 214)

Two participants felt that their professional status contributed to the way in which staff respected their views.

I think it helped being able to put on my NHS badge and they sort of realised then that you are a professional as well (P8 304)

There was also a feeling that being qualified ('in the know') has its advantages

because you see, if you haven't got the nursing background, us as nurses, we know what to look for (P7 372)

Family carers as well as professionals could also feel empowered. One participant contrasted the recent positive experience with previous negative experiences and talked about the role she had played when formally asked to provide some training to staff.

so I had to talk to them about, sort of our experiences, you know our problem at the time andI think that the value of training as many people as possible means that

the word gets passed around, it changes people's perceptions and attitudes (P3 779, 824)

This parent participant felt that her input into the training of hospital staff in general had had a significant impact.

Nobody described that they received an inferior service as a direct result of the learning disability. In fact some people felt that led to preferential treatment.

We waited less, I can guarantee that,.....because of her special needs. Obviously because we were told to mention she has special needs. I'm sure it did help. (P6 259)

Sometimes people described situations where they seemed to be passive and did not question what was happening, like the participant whose adult son spent 48 hours in the emergency department

Researcher: *Did anyone explain why he didn't go on to a ward first?*

No, No, I just assumed it was because they hadn't got a bed for him (P1 67)

Some experienced a feeling of being powerless and wholly reliant on others

Researcher: *Could I just check that did the triage nurse do anything, she just took details from you, she didn't look at the wound?*

No she didn't, I actually had to ask her for more dressings because Kelly was still bleeding and I used up the dressings that the ambulance guy gave me, no she didn't. She did ask about blood pressure..... ,but no she didn't look at the wound, no she didn't, she just sat there by her desk and I had to ask for dressings, which she gave me and then she sent us back out (P11 77)

1.4 Keeping carers informed

What could contribute to feelings of being powerless or not feeling valued was when participants felt that they were not kept sufficiently informed. Carers felt better treated

when staff introduced themselves by name and profession. There was one occasion when this did not occur.

but no I find no there's not even "Look my name is", or "You are Kelly?"

[and later]

I didn't even know the doctor's name, I just assumed it was a doctor (P11 256,305)

This appeared to have been an isolated example and may have been related to the difficulties already mentioned in this case where staff reported being under pressure due to a previous emergency. No other participants described a lack of introductions and in fact many talked about how both nurses and doctors introduced themselves by first name as well stating their profession. This made carers feel that staff were more approachable.

introduced themselves by their Christian names and so on., "Hello Malcolm, I'm Duncan the Consultant" and that sort of thing (P2 39)

They do introduce themselves, one thing about A&E is that you very often see a number of different people but they do come over and introduce themselves, and say "I'm doctor so and so" (P3 1213)

The time when people most wanted feedback was during periods of waiting. Whilst only one of the participants felt that they had to wait an unreasonable length of time for an initial assessment after arrival, many commented on the waits later in their journey through A&E- particularly if they were waiting to be admitted to a ward. The wait per se was not the issue but the lack of information about what was happening.

you are just hanging about, hanging about, the time does drags so and you have nothing to do but sit there and look at each other, that sort of thing. I think perhaps occasionally you have to accept that they are very busy but occasionally if they could just pop by and say "Everything's going all right, sorry about the delay" but otherwise -you know that sort of thing. But you have to relate that to how busy they are. (P2 168)

Being kept informed that you might be in a side room for a little while, without anybody coming so you go to search people out and they are all congregated around the desk. I know they are very, very busy but then you feel annoyed because nobody has come to you. (P5 593)

One service user was asked to return to A&E and given an actual appointment time. However this time was not adhered to and rather than complain about the wait, the participant response again referred to the need for some feedback from staff

we were waiting an hour and a half for that appointment time with no explanation. We assumed OK they are working on other people, but it would be nice if you had some indication. I think we would all wait with a better grace if you knew the reasons (P3 709)

If staff did explain the reason for a delay or apologise, to a certain extent this seemed to make it ~~more~~ bearable

they said that they had got to admit him... we are now waiting for a bed. Sister said "You could hardly turf somebody out of a bed". You've got to wait for a bed haven't you? (P2 57)

The paediatric doctor was very good, he apologised for us having to wait (P10 82)

Similarly if participants asked a question of A&E staff they found it difficult if they were promised an answer that was then not forthcoming. Presumably in a busy department it can be difficult to remember to follow up on people's requests and queries but it clearly made people feel uncomfortable if they needed to persist to get a response.

I had to keep on asking and then I felt like the one who was nagging them (P 4 165)

Sometimes non clinical staff would help with this situation.

the receptionist said to me “Has anybody seen you” and I said, “No”. She went off, she come back again, “Right”, she said, “I’ve gone to find a nurse, the triage nurse” and we finally got to see her..... the receptionist ... she was brilliant (P11 41, 235)

2.0 Emotional responsiveness

Another Master Theme that emerged was one of Emotional Responsiveness. This was more than treating people with respect (i.e. making them feel valued) but involved compassionate behaviour which the participants clearly appreciated. Those who felt cared for were more likely to speak positively about their experiences.

2.1 Nurturing (caring)

When speaking positively of the service, participants often illustrated this with descriptions of nurturing attitudes or gave examples of staff going out of their way to accommodate the service user

I’ve had the consultant in charge at A&E down on the floor with Sharon working on her with me. Because he said “If that’s where she wants to be we will carry on down there”. I think it’s great. (P3 206)

or showing flexibility

after we had been there 1 ½ to 2 hours, Julie was fed up of sitting in the bed and I did ask one of the staff on duty whether it would be OK for me to take her across to, there was like a patient lounge area which I believe was for relatives and she said “Yes that would be fine” and she brought a chair over and it was wonderful that Julie was able to sit in there and it was a lot less clinical (P8 125)

Sometimes participants just described an overall feeling of the staff being caring, making general comments,

they were really good, the staff, really good. Everyone was pleasant and friendly, very, very kind (P10 199)

they gave Julie some toast and they gave me some toast and a cup of tea and everything. We were well looked after, they brought some magazines for her. I felt generally they did what they could under the circumstances, you know, to be helpful (P8 295)

They were occasional reports of A&E staff not responding to a service user's 'emotional needs'. One carer who arrived at the hospital after the service user had been admitted to A&E found the service user distressed and calling out. The staff had dealt with him from a medical perspective but did not appear to be responding to his emotional need for reassurance – his panic apparently being triggered by an unfamiliar type of bed

He was shouting "I can't feel my feet"..I just stayed there with him and reassured him and actually put his foot into the place where it should have been. (P7 106)

Another participant talked about how she would have liked to see more evidence of nurturing,

just people saying "Is there anything we can do to make it comfortable for you" because she might become distressed by having to wait. And just checking whether someone is too cold, they might need some extra blankets while they are sat there, instead of having to seek them out (P5 344)

Another participant made numerous references in her account of asking the staff when the service user could have a cigarette and some food and drink. As she recounted her experience, so the participant's report became increasingly frustrated presumably mirroring her change in attitude during the actual experience. Early on in the narrative she is describing what the service user wants, but she understands why the staff cannot provide this.

well we got there at about half past four, he had his x-ray about half past six, Jez was becoming very stressed because of Jez's learning disabilities. He suffers from schizophrenia, autism and I was explaining to the nurses he needs to have a cigarette they wouldn't take him out for a cigarette because they didn't know the situation on his ankle, which was fair enough, so Jez waited patiently (P4 29)

A little later she is concerned about his lack of opportunity to have even a drink – she no longer justifies the staff decision but apparently does not challenge this.

he had been treated I would say about 8 o'clock, no probably about 9 o'clock. He had nothing to eat all day, no water, because they didn't want to give him anything but he was like really hungry because he hadn't eaten until like lunchtime and I said could he have a drink but they wouldn't give him anything (P4 43)

As her story unfolds she becomes openly critical of the staff and clearly far more likely to challenge them. Her focus then is still on the service user's needs.

Jez was getting really stressed out because he needed a cigarette because this is a guy that has a cigarette nearly every half an hour and its routine.....and I was sick of asking the nurses, I was like that, "When can he go to a ward so he can have a cigarette?" and "Oh it will be in a minute" so we waited about four hours for him to find a bed -without no food, no drink and no cigarettes. (P4 54)

In the final quote she gives some insight to how the situation was for herself trying to care for someone who is relentless in his demands – which she is unable to meet.

He was like repeating it, "When can I have a cigarette, when can I have something to eat". It was constant (P4 195)

2.2 Empathy and Understanding

Another theme that emerged was the level of empathy and understanding that participants were describing or demonstrating in their accounts. Some of this empathy was directed from the A&E staff towards service users. This often involved acts of kindness that went beyond a basic nurturing.

The client was obviously taken with him [doctor] because he leaned forward and put his arms around him. The doctor responded. It was lovely, really nice. (P9 87)

What was also noticeable was that the participants often empathised with staff or were sympathetic towards them. This sometimes related to participants' understanding of having to wait. The longest time periods seemed to be when people were waiting to be admitted from A&E to the main hospital but participants appeared quite stoic and understanding about this.

You can't do a lot to hurry that sort of thing up and I think they did all they could. (P2 58)

Waits were not attributed by the carers as being related to the fact that the service user had a disability but to the medical need of other patients within A&E

they have notices up to the effect that the most serious cases will be seen first. Now that's understandable and it's right. (P3 622)

or to how busy the hospital was

I think really it [the wait] was a lot longer, for someone with Jez's condition as well.

Researcher: *And why do you think that was? Why would he have been kept waiting longer do you think?*

Probably because they were busy and I think they were looking for a bed as well. (P4 245)

If we waited longer than anybody else that was nothing to do with Malcolm, that was just how busy they were sort of thing and the availability of a bed perhaps (P2 232)

One participant felt that staff had not communicated sufficiently with her as a carer adding,

but I suppose in A&E it's so busy isn't it? When you get back on to the wards it's a little bit, it's more relaxed isn't it, because they have got the time. (P1 181)

She also felt that there was not enough time given for explanation but again attributed this to the nature of the department

I suppose really because, because of the situation, as you know in A&E they are busier sometimes than others (P1 369)

Another participant, whilst outlining the importance of direct communication with a service user, sympathised with the staff if they did not use direct communication

but I can also understand how sometimes the staff don't because they are not really sure if they are going to understand themNo it is difficult. I can remember when I first started in the job I had never had anything to do with anyone with a learning disability and they were all adults and I thought oh great, but I soon learned that you can't just speak normally, initially, until you have realised their understanding (P9 321)

There was also recognition for the difficulty of the staff's job

There was ever so much going on. How they cope I do not know (P2 180)

made more difficult by the addition of trying to assess and treat someone with special needs.

..they do try always. I have always said to the staff and we appreciate their difficulties because if I had to deal with somebody like Sharon who I was meeting for the first time then it is very difficult (P3 197)

I think they are terrified of traumatising her really and she can throw herself around a room quite violently and then they are terrified of restraining her because of all the restrictions placed upon them. I feel for them. They do their best. If necessary I will hold Sharon in the best way that I can to prevent her from injuring herself and then I know it relieves them of the worry and responsibility (P3 274)

Participants were also empathetic towards the service users. Frequently they were concerned with the potential lack of understanding that service users might have in relation to waiting, but also participants were acutely aware that the service users were not able to eat and drink. Therefore carers felt they could not do this in front of the service users

well I had a bag of crisps and a can of coke and I couldn't eat it in front of Jez because he was starving (P4 193)

I would not leave Kelly, no, no. And nothing to eat or drink (P11 369)

2.3 Recognition

Participants also believed that it was positive if they were recognised from past visits. This seemed to make people feel that they were seen as individuals with whom staff had made some emotional connection rather than just one out of numerous ‘faceless’ patients.

She [nursing sister] remembered, she said, “Of course, Malcolm you were right at the end weren't you..... you had to wait such a long time didn't you because we were busy?” So what I'm saying is there was immediate recognition. (P2 192)

It was also useful in terms of staff becoming familiar with the service user and her personal needs

We're lucky because we're quite well known to the hospital..... because Sharon has been there fairly often in her life, there are staff there who know her, we've got a head start in that direction (P3 166)

3.0 Support

Participant discussion often centred around the support provided to the service user by themselves or other people, the support that they as carers offered to the staff and the support for themselves. They talked detail about the support that they themselves either had or would have wished to have whilst in A&E.

3.1 Support from the carer to service user and to staff

Most participants felt that A&E rely quite heavily upon carers in supporting communication and in providing reassurance to service users. Participants saw this as their role and most expected to remain constantly with the service user. Sometimes they were expected to assist with the treatment and the response to this was variable. For example a fairly slight female carer who had accompanied a tall and heavily built service user said,

I had to hold Jez's leg up for 10 minutes while they cut the plaster off because there was no one there to help (P4 411)

Whereas another participant was pleased that her husband and adult daughter were able to position the service user's hand in order to obtain the x-rays required.

Some professional carers felt that their input should be recognised

Because if T's [Liaison Nurse] not around I think Nurse Managers should realise that, I mean we are very supportive (P7 576)

Only one participant was not relied upon for support by staff. This was an older parent whose son had to remain on the emergency department for 2 days until a bed became available on a ward. As he did not require constant 1:1 support, retrospectively his mother believes that staff considered his hearing impairment as being his only disability and mistook him for being more intellectually able than he actually was

You see at that stage it probably wouldn't be noticeable (P1 31)

Not only was he asked questions which he could not understand

It's like when the doctor said to Monty, "Are you allergic to anything?" he hadn't got a clue what he meant (P1 192)

but staff also thought that he was non compliant with his medication whereas he had apparently not understood its purpose.

Support was not only of a practical nature

Obviously she [service user] looked to us for reassurance and we obviously had to say

"Yes that's fine" (P6 133)

3.2 Equipment

Most carers, as mentioned before, felt obliged not to leave service users even for very short periods. This was sometimes for practical safety reasons because the hospital equipment was inadequate to support the needs of the service users.

One participant commented that he had asked for but was told there were no available cot sides for the hospital bed. The carer coped with this by not leaving the service user unattended at any time. However whilst he sat with her, another patient (elderly as oppose to learning disabled) attempted to climb out of bed and fell. The carer therefore felt that wider availability of cot sides was important.

Another carer used a hospital wheelchair but said there were no straps which made it difficult for the service user to be adequately supported

and these are massive wheelchairs in Y, with her facing me like this, so I was sat like this and I will say at the end of how many hours I was there I had appalling neck ache, backache.....because I was frightened that if she had a seizure she would go straight forward.....For two days I did have chronic neck ache and you do ache and I had to keep standing up, sitting down, because of the position I am in (P11 394)

3.3 Liaison Nurse

Only one of the two hospitals employed a Liaison Nurse therefore this service was not available to some of the participants. In the hospital where this post existed it appeared that only one participant was unaware of the service. This was the participant whose son's learning disability appeared to go unrecognised and this would account for why staff did not involve the Liaison Nurse. Another family was not offered Liaison Nurse support, but as they felt that they had an excellent service they had no concerns about this. In this case one would assume that the A&E staff were aware that the service user had a learning disability given he had Down's syndrome. It may be that staff are selective and only use the Liaison Nurse if they believe there is some necessity or added value in doing so. Alternatively staff may have been aware that she was not available on this occasion or those particular staff providing treatment may not commonly seek additional help. Two professional carers also did not have access to the Liaison Nurse as she was not at work during the times of admission. However both these carers had experienced support from her in the past and had much to say on the subject.

I have met T [Liaison Nurse] before and she does know Jez and she is brilliant. T. is really good. But T. wasn't on call then.....she wasn't there because it was a Saturday and she wasn't on and there was no other [learning disability] nurses.

Researcher: *Do you think it would have made a difference if she had been?*

Yes, definitely because she would have been more straighter with the nurses and she would have told them (P4 71)

This professional carer felt that the nurses were not always responding to what she was saying and that the Liaison Nurse could have helped with this. When later summarising her experience she said,

I was upset that T wasn't there as well to give me the support (P4 566)

The other professional carer also spoke positively about the Liaison Nurse from past experience. She arrived at the hospital from home having been alerted by her staff that the service user had gone to hospital by ambulance. The service user was therefore without a carer for a short period and the participant expressed a wish that the Liaison Nurse had been available. It was the participant's belief, from her previous experience, that whether the Liaison Nurse knew the service user or not, her background in learning disabilities was very valuable.

The remaining three participants (all family members) had support from the Liaison Nurse for the episodes of care they were describing.

A family carer, who herself was a qualified Learning Disability Nurse and the professional carers, highly rated the presence of Liaison Nurse, despite their own experience in learning disabilities. Participants thought this related to her position of authority within that particular hospital. It was also noted that she could contribute to the medical notes. Some felt that it was important that the liaison post was filled by a nurse as most of the advice and negotiation was being done with nursing staff.

Obviously her skills from her nursing background has obviously helped enormously (P5 578)

They also felt that the individual herself had particular skills which had allowed her to develop positive relationships with hospital staff.

well I work in learning disabilities and I think if I go down there I've got the skills to be able to move things on, but not in the same way as T. [Liaison Nurse] has. She has just got such a good relationship with people and the doctors (P5 568)

One participant commented that the Liaison Nurse was good at explaining procedures to service users which helped with consent to treatment.

Several participants wished that the Liaison Service was available at all times and not dependent on one part time individual. One participant felt that if it was not possible to have a Liaison Team i.e. liaison staff providing 24-hour cover, then perhaps hospital staff could spend time working with the Liaison Nurse.

I think it would be great for some of them [hospital staff] to shadow her and get an understanding of how she is working and how to talk to people around all the issues of supporting someone with a learning disability (P5 535)

Another family, having been unaware of her existence before, felt there should be more awareness raising of the post. However they felt this might need to be directed at local parent carers outside the hospital setting, rather than advertised within the hospital, as they felt she might be inundated by requests from families where there was not a global learning disability but maybe some other difficulty.

Participants talked of the Liaison Nurse's support for them in negotiating with staff and taking away some of the responsibilities that would otherwise have fallen to them. There was a clear need for the participants themselves to be supported e.g. in the all the cases where there was a mother and father living at home it was noted that both parents went to A&E. Furthermore sometimes other relatives were also asked to provide additional support.

The Liaison Nurse was also perceived as somebody who could facilitate a process

she came down very, very quickly.....when she comes now she explains exactly what is going to happen and what the next process is and she can actually get things moving quite quickly (P5 87)

and who could provide some continuity by being present at follow up appointments and could create solutions or make suggestions which were subsequently listened to by hospital staff.

..... this is where we couldn't have done anything but T. can because she is in the hospital. He [the doctor] said to T, "Here's my pager number when she is going down, call me, I will come to theatre, have an x-ray team available, we will do some better x-rays than we have been able to get with Sharon awake and we will do it in the theatre while she is there for other reasons". That's how it went. It was terrific..... Whereas you see when I asked the GP he just said,..... .. "It would be impossible, its different departments and it wouldn't work" (P3 453)

The participants themselves appeared to have the ability to communicate with A&E staff and to suggest organisational changes, but felt that hospital staff perceived suggestions as more legitimate when coming from a professional colleague.

4.0 Compliance

Whilst participants did not spontaneously discuss consent during their narratives, when specifically asked about this issue they had much to say on the subject. Even though the term 'consent' was used by the researcher often participants were talking about compliance as oppose to consent.

We were asked about what she was likely to comply with and they did say would it be possible to do an ECG and I said that it would be unlikely that Julie would comply with that. (P8 231)

The participants seemed more concerned that the A&E staff explained to the service user and that the service user was compliant - rather than the staff seeking the service user's informed consent.

The doctor explained to the client and to us what he thought was wrong, you know, what it was and how he was going to treat it, which the client was quite happy with. How much he actually understood, I don't know. I mean he seemed to understand. You

know, "We are going to take this" and he was fine. But I would say that, yes he explained to the client and us. I don't know how much the client understood (P9 264)

If the service user was more likely to be compliant, if they were less aware of what was happening, this too was seen as reasonable

I mean it was like with the blood pressure, I said we can probably get her blood pressure if we move the machine from her sight (P8, 234)

On the opposite side of the coin, a lack of compliance from a verbally able service user was perceived as refusal of treatment. One carer said that there was an assumption made by staff that her son understood the treatment plan, whereas in reality she did not believe he did. He was the only service user who did not have a carer permanently with him in A&E and initially he refused to take the medication offered.

...on the second day, um, it transpired that he hadn't taken his medication that he was supposed to take, which then, of course, was making him more agitated, um, and I think it, the main reason was because nobody had been and explained to him I explained it to him and then it was OK (P1 81)

However a reluctance to comply on the part of non verbal service users was not seen as a refusal to consent to treatment. Staff continued to attempt to treat even when the service users' non verbal language suggested that they were not consenting. This may have been because the assessment or treatment was considered essential.

she goes pop-eyed and her last resort is to slide out of the chair and down onto to the floor. I've had the consultant in charge at A&E down on the floor with Sharon working on her with me. (P3 207)

Participants made the assumption that by presenting for treatment, provided the treatment had been explained and the service user was not verbally objecting, that the service user was consenting for that treatment.

Well, I suppose really by us saying, taking her and saying please have a look at this, I mean, you know, we said "Yes try and see how you get on" (P3 1021)

Participants also seemed to feel that consent was more of an issue for planned hospital procedures: either because the treatment in A&E was not considered a major medical intervention

Researcher: *did you feel it was necessary to ask for consent?*

No, not really. It was only like a facial injury really (P 6 364)

or because of the emergency nature of the situation or physical condition of the service user

I would say that it was a necessary procedure so the medics would have made that decision (P7 475)

This attitude may be true for the general population as it does not appear to be the practice of A&E departments to formally ask any member of the public to give verbal or written consent. In contrast written consent is required for surgery.

Only one participant specifically recalls having been asked whether the service user could fully understand the procedure and was agreeing to the treatment. There was an assumption in this case that verbal consent was about compliance and written consent implied an informed understanding.

She had to give verbal consent. She wasn't asked to give written consent because they checked that with us.

Researcher: *What did they check with you?*

Whether she was actually capable of giving informed consent.

Researcher: *And you said yes?*

She couldn't give informed consent she wouldn't understand the whole process of that but she is able to give verbal consent because she has refused on many occasions over a number of things, so she is quite clear about yes or no. Often she will say "Sure" to let you do something but if she didn't want a process to happen then she would make it very clear.

Researcher: *And did Kate understand what was being asked of her on this occasion do you think?... ..*

No, we had to explain it in words that she would understand, so we had to rephrase.
(P5 473)

Another participant recalls being specifically asked if the service user was capable of giving consent. Perhaps significantly this was the service user for whom the carer had predicted sedation would be required.

One participant felt that staff had a better understanding of consent issues than they had previously within this hospital,

well up on this one now (P3 1013)

explaining how staff got down with the service user asking if it was okay to look at the injury etc. Others thought that there may still be confusion for hospital staff in general as to who can give consent to treatment for an adult service user,

they seem to think a parent or a guardian or the carer can give consent and I think they need to realise what their responsibility is, because as a professional worker, I am able to say that I'm actually not in a position to give consent and this is how you need to go about doing it. But obviously if it was a parent who came in with their adult child..... then they would probably sign something and staff from our house have signed, in the past, consent forms and I've had to say "Well hang on you're not actually able to" (P8 258)

I actually think people don't understand fully about capacity and consent, particularly in light of the new Mental Capacity Act that's come in (P5 500)

This participant further commented that families themselves still do not either understand or agree that parents do not hold this right for adult offspring.

Dad just thinks it's silly to ask, you know, if we've got to give her medicine through a tube then it has to happen..... He thinks it's absolutely crazy - that we should be able to just do this because it's going to make her better (P5 507)

One professional carer demonstrated her lack of knowledge as relates to consent,

Consent is a huge area with learning disabilities and I just think, I think you have to go through the nearest carers, so the parents, if you want to do a procedure (P7 485)

Some participants were also aware that compliance might be variable

if the doctor had said "I'm going to do this such and such is that OK?", he would have probably said yes. Or he may have said no. I don't know whether, to be honest it would have depended on the way he was feeling and his particular mood at the time (P9 276)

whilst others seemed less aware that consent or compliance might not only be affected by the mood of the person but also that someone might wish to consent to one intervention but not to another. One professional carer thought it would be a good idea to have a 'blanket' consent prepared.

if during a review we brought up the consent issue, so you've got professionals, care manager, parents, sometimes the service user,we could have a consent form that we hold. (P7 503)

Carers talked about who might help with the process of explaining to a service user. In one case the participant had arrived at the hospital after the service user by which time some medical procedures e.g. blood test had already been undertaken

Researcher: *If somebody had asked Paul "We want to take your blood, is that OK?" would he have understood what that meant and what that entailed?*

If I wasn't there he wouldn't. Or not just me, a member of staff really. (P7 418)

Some people thought that the Liaison Nurse played an important role in this process by helping service users understand potential treatment,

T. is just fantastic she's just so good at explaining everything, very clear and she will show things to Kate." (P5 481)

For many participants as long as staff explained what they intended doing or gained agreement from a carer this seemed satisfactory.

5.0 Responsibilities

Throughout the narratives participants often made references to issues of responsibility. This took different forms. Participants talked widely about the responsibilities that they felt that they had to the service users that they were accompanying but also frequently mentioned their duties towards others and how they had to balance these. They also had clear ideas about the roles and responsibilities of the hospital staff.

5.1 Risk taking & management

In some situations participants had to manage and indeed take risks. Some of these have already been described in the preceding sections. Often participants managed risk by choosing to stay with service users which prevented them from going to the toilet, eating food or having a drink, because they considered that the environment was unsafe. Many family carers went in pairs (or in one case, four adults) which would allow for breaks, but in only one case did the professional carers have this option.

Sometimes participants were placed in a situation of not being able to accompany the service user in the ambulance so that initially he or she was unaccompanied on arrival in A&E.

This was always related to having other dependents. One professional carer had to be phoned at home and asked to go into hospital to support a service user as there were insufficient staff on duty in the respite service for someone to accompany him.

the ambulance just took him in.....

Researcher: So he travelled in without any staff, and you got there as soon as possible?

Yes, because it would have been night staff you see and also relief staff. In normal events we would try and send somebody always in, you know, one of us would cover each other to go in but because of the timing, it was very early.

Researcher: So he went in on his own,Was he a client who needed somebody with him?

Yes, he has additional staffing here. So from 8 o'clock [in the morning] until 10 o'clock at night he has one to one. (P7 73)

One parent carer who had two sons with disabilities commented that it was fortunate her husband was at home when the ambulance was called.

I was lucky there were two of us here when it happened. My husband followed by car, that means he could take our other son with him. If I had gone in by ambulance well I wouldn't have been able to get home and I wouldn't have known what to do with my other child - so I am not sure how that would work out. (P10 208)

Sometimes participants had very difficult decisions to make. One described how she had to decide whether the service user was to be transported to hospital by ambulance, which would be faster, but would she felt inevitably result in the service user becoming distressed and destructive. The alternative was to take a longer journey by car with a potentially difficult service user, who might have another seizure and who was bleeding from a wound, in the hopes that her behaviour might be calmer in the more familiar environment.

It takes forty five minutes to get to Y. And you think that's easy enough and that day I brought her in the car as she would be too stressed in an ambulance. The last time she went in an ambulance there were 2 or 3 staff with her.....that's fine, that's through the day but when you are on your own. When she's got a belt on in the car she's OKAnd if she has a seizure or what, obviously you have got to weigh up the pro's and con's to take that risk because I thought going in the ambulance on my own if she has a massive wobbly in the ambulance she will just trasn it and what am I going to do. (P11 206)

The responsibility of making a decision like that described above is enormous, particularly for non qualified paid care staff, who may additionally be held liable by an employer in the event of an untoward event. It is perhaps unsurprising that such staff then find it difficult if on arrival at hospital they find that no-one appears to be taking effective control and they themselves feel powerless to do so.

One participant, accompanying a relatively able service user, described how she believed that she was made to feel responsible if he were to refuse medication or discharge himself

She [A & E nurse] said "Of course, if he refuses to take his, um medication" she said "Or if he wants to discharge himself, you realise that there is nothing that we can do about it" So of course, I laid awake then all night waiting to see if the phone rang. And um, from then onwards then because of my concern I went up early each morning and stayed with him the whole of the day (P1 92)

5.2 Medical care including pain issues

Once participants arrived at A&E, although they clearly saw that they had a role in practically and emotionally supporting the service user, they saw the medical responsibilities as being with the A&E staff. Some participants who were from a nursing background were pleased to be consulted but nevertheless looked to hospital staff for the lead. None of the participants criticised the medical care or treatment that was actually offered – although in one case the delay for even an initial assessment and the lack of intervention was considered by the participant to be extremely poor. This participant, who reported waiting over 2 hours before being seen by triage, then apparently waited a further hour for a doctor. Although she described that by the time she saw the triage nurse, the service user's wound was still bleeding she was adamant that nurse had offered no treatment.

Participants felt that the staff had a medical responsibility to deal with any pain. Most service users were asked directly whether they were experiencing pain but participants, although they welcomed that direct communication, also recognised that pain can affect the traumatised person's ability to communicate.

Also some participants noted that people with learning disabilities do not always show pain in a conventional way.

We think it's something to do with the endorphins, she gets quite euphoric on it, she gets really happy and it's just something that always happens after head injury but after a while she can't stop rubbing (P11 150)

Some service users were able to point, others were able to communicate pain either verbally or nonverbally e.g. through crying. Sometimes staff would ask the carers how the service user expressed pain. Participants were specifically asked by the researcher, not only how A&E staff determined whether a service user was in pain, but also how staff located and gauged the severity of this pain. Some carers pointed out that the injury was very obvious; another said that as the location was fairly external the service user was able to explain, but had it been an internal pain she does not think he would have had the skills to do this. On no occasion did carers report that any measures were used to try to determine the severity of pain. However participants felt that this was obvious from the injury or from the service users' behaviour.

Participants were also asked about the use of pain relief. Sometimes pain relief was given and sometimes not and 10 of the participants felt it was neither unnecessarily prescribed nor withheld when it should have been given. However the participant accompanying the client who tends just to rub an area when she is in distress did not feel that the staff had discharged their responsibilities adequately. Despite the fact the carer informed staff that in her opinion the service user was in pain, no one specifically asked the carer or the service user about pain or offered any pain relief. Although the participant admitted that this particular service user is difficult to treat, in the past she has successfully been given pain relief orally by syringe or in jam. Other participants talked about how service users will not/cannot always take oral medication and that sometimes pain relief might have to be offered in a different form.

she won't take any medicine orally I don't think she was taking any in A&E because whilst on the ward when she was refusing that, they were actually giving it to her through her stomach while they were tube feeding her (P5 450)

A number of participants suggested that staff might find out more about the severity of pain if they used an aid such as smiley and sad faces, but acknowledged that this would not necessarily be appropriate for all people with learning disabilities.

CHAPTER 6

DISCUSSION

The aim of the work described in this thesis was to explore the A&E experience of service users with learning disabilities, as viewed by their accompanying carers.

The experiences of 11 people were analysed and 5 Master themes were identified: Interactions that are Valuing, Emotional Responsiveness, Support, Compliance and Responsibilities. Some of these Master Themes had a number of sub themes.

1.0 Current findings and their relationship to past research

1,1 Interactions that are valuing

Within this study it was apparent that when participants made reference to communication this was often in relation to whether staff made the effort to involve the service user. If they did so, this was perceived by the participants as valuing. Participants acknowledged that there were barriers to effective communication but they did not always attribute this to the learning disability but also to the presence of sensory impairments, or as a result of the trauma or medication given following this. However participants did not perceive these barriers to be a significant problem provided that they, the carers, were there to support the communication process. In fact in an ironic twist one participant described difficulties in the opposite direction.

There was an African doctor..... I think he was African. I am not being funny or anything but the boys really couldn't understand what he was saying. He was very nice. We had difficulty understanding what he was saying (P10 73)

Hart (1998) identified 'Communication about Treatment' and 'Understanding' as being key issues. Perhaps significantly, Hart's work involved interviewing verbally able service users rather than carers. Whilst her work did not focus around A&E, the more recent work by Sowney & Barr (2007) has done just this. Communication also emerged as a theme within their research when A&E nurses discussed their experiences of treating people with learning disabilities. In the study by Piper (1999) A&E staff talked about their lack of confidence in knowing how best to communicate without appearing patronising. Whilst issues around communication run throughout all these studies, comparing this research with the literature does suggest that A&E staff and service users may be more concerned about understanding one another. In contrast carers seemed confident that they could facilitate this process and focused more on direct communication as being a respectful way to interact with an individual.

Being kept informed also proved to be important to the participants in this study. This was linked with feeling empowered and valued. Participants appreciated staff briefly introducing themselves. If participants knew with whom they were speaking they could be clearer what information to share and what to ask about. In addition not knowing to whom one is speaking seemed to engender feelings of confusion and helplessness. These are relatively simple changes that could be made but ones which might significantly improve people's perception of the standard of care.

1.2 Emotional Responsiveness

Participants in this current study considered that demonstration of nurturing was synonymous with a good service and one which indicated that staff were emotionally responsive to the service users. Hart (1998) also identified General Nursing Care as an issue for service users within hospital. There is evidence to suppose that a theme around Nursing Care is not specific to service users with a learning disability. Nyström et al. (2003) determined that service users in general felt that there was too little emphasis on 'caring' in A&E - with nursing staff focusing on practical care.

In this study there were numerous examples of staff behaving in a nurturing way and demonstrating an emotional response to service users that often went beyond basic care. Whilst most participants were describing nurturing experiences, there were a few instances where this was not the case e.g. the participant who complained about a

service user having no food, drink or cigarettes for hours following treatment and whilst awaiting admission. This had a profound affect on the way that this participant viewed the service and may have been particularly distressing for her, because she felt prevented from meeting the basic requirements of someone in her care.

Generally there was very little distinction between the different professions within A&E. Participants who felt that they had received a good service spoke positively about reception staff, porters, nurses and doctors alike. The few who were less satisfied tended to feel negative towards both the nurses and the doctors – though not towards the other staff.

One of the most striking features of this research was that staff attitudes, which have been described in previous literature (e.g. Slevin & Sines 1996) as problematic and impeding a good quality service to people with learning disabilities, did not appear to be an issue for participants. Staff relationships with both the carers and with the service users did appear to be an important factor for those interviewed. Obviously the two issues are related as a negative attitude towards learning disabilities will inevitably impact on the type of relationship a member of staff will develop with an individual and carer. However ‘attitude’ and ‘relationship’ are different. There was little indication in the information gathered that participants believed that staff felt negatively towards the service users as a result of the disability [attitude]. Rather participants’ perception of the quality of the service they received seemed to be related to the staff’s levels of warmth, demonstration of ‘humanness’ and the amount of communication with participants [relationship]. This is in direct contrast to a previous study in one of the same two hospitals in which carers had frequently suggested that service users were not treated in a humane way and believed that this was directly related to the presence of a learning disability (Piper & West 1998). Participants themselves acknowledged that there have been changes.

I think there is a real determination in X hospital in the A&E department now to provide the best that they can under the circumstances and I've not come up against anything that has upset me (P3 675)..... and later

I mean there is a different attitude I think..... (P3 721)

There was indication from the current participants that the amount and quality of interaction between hospital staff and service users was greater than that described in past literature in general (e.g. Mental Health Foundation 1996, Tuffrey-Wijne et al. 2005) and better than that described in Service X in 1998 (Piper & West 1998). In Nyström's study (2003) there was evidence of A&E staff focusing on quantity as opposed to quality when working with the general public, but this finding was not replicated within this study for people with learning disabilities, as many felt that time was set aside for communication and efforts were made to engage in relationships with service users. When this was not the case this appeared to be related to the situation in A&E at the time rather than staff attitude to the presence of a disability. The question this finding raises is whether the previous literature that described relatively widespread negative staff attitudes towards 'learning disabilities' is now less relevant and whether there have been significant changes in the attitudes of hospital staff. If this is the case one might seek to identify the catalyst for this change. Staff in one hospital had received training in the form of Total Communication and had the potential of a role model in the form of the Liaison Nurse. However the other hospital had received none of this input and yet, whilst it is acknowledged that this is not a comparison study, similar responses did seem to emerge. It is possible that recent developments in nurse training (such as Project 2000) have promoted positive attitudes through increased learning disability focus within the curriculum. Alternatively the growing number of people with learning disabilities presenting to mainstream hospital services may have helped staff become more familiar in dealing with this client group - the assumption being that unfamiliarity causes concern and discomfort leading to negative attitudes (Slevin & Sines 1996). Another explanation is that society in general (not just hospital staff) either has a more positive attitude towards disability or that members of society, particularly those in public office, behave in a more positive way in order not to be perceived as discriminatory. If it is just the latter, i.e. an attempt to appear non-discriminatory, it is questionable whether staff would have been demonstrating emotional warmth, which is what was apparent at times between staff and participants. Sampling just 11 participants in a specific department (A&E) across just two hospitals based in the same region is not sufficient to clarify whether this finding represents a general change in attitudes. One would need to consider this in a wider study.

Another issue that emerged from this study was that A&E users can be discriminatory and very understanding about waiting times. Hospital staff and others had queried whether waiting times would always be a bone of contention for any user (with a disability or otherwise). This is rather reminiscent of the research question, 'Can parents ever be satisfied with a diagnostic process whereby they learn that their child has a disability?' The assumption that parents would always find this difficult and would therefore be likely to rate themselves dissatisfied with the diagnostic process, allowed professionals for some considerable time to ignore quality issues relating to the service that they were providing. Studies, such as that by Cunningham et al. (1984), dispelled this myth by showing that parents can discriminate between the information that they are given and the way in which this is imparted. Similarly this study suggested that, whilst none of us would wish to wait for long periods following an accident or injury, carers do not indiscriminately complain about waiting times. Only one carer expressed concern about the length of wait for an initial assessment and there seems to be some justification for this as staff themselves apologised and explained that they had been dealing with a major medical emergency. Of concern was the length of time taken for service users to be admitted to a ward after A&E treatment. These findings are consistent with those of Downing et al. (2004). A&E do not refuse to provide a service due to lack of capacity and they continue to add trolleys etc to the department in order to manage capacity problems. Wards however appear much more likely to say they have no bed space which further adds to the capacity problems of A&E, rather than impacting on the main hospital. However participants in the current study did not view this as the fault of A&E and were very sympathetic to the pressures they perceived staff to be facing. The only criticism of them, in relation to this, was their lack of feedback to carers and service users about what was happening or just some reassurance that they had not been forgotten. Whilst this feedback to people waiting for admission is an issue of good practice and one that could be relatively easily resolved, one has to sympathise with A&E departments as they are effectively having to manage a problem that lies with the wards of the main hospital for a group of patients whom they have already assessed and with whom they have finished treatment. Piper & West (1998) found that in their previous study, carers did complain about all aspects of their wait in A&E including the wait for treatment. Furthermore carers related this to the fact they were accompanying someone with a learning disability. In actual fact when this was explored further it transpired that people with learning disabilities were either waiting a comparable length

of time to others with similar treatment requirements or alternatively were actually being fast tracked. In this current study carers attending the same hospital no longer felt they were kept waiting longer than others which suggests that if the general service quality improves, the meaning carers attach to their experiences may also change.

1.3 Support

Participants in this study felt that it was appropriate and helpful for A&E staff to see them as a source of information and expertise and they seemed to find it valuing when staff sought their advice and worked collaboratively with them. Sometimes participants did feel that A&E staff lacked specialist knowledge, but provided that they took advice from the carers this was not seen as a major issue. These findings are in keeping with Sowney and Barr's research in 2007 with A&E staff themselves who raised issues of Dependence on Carers and Lack of Knowledge. Although participants in this study felt that it was appropriate for the hospital staff to see them as a source of support e.g. in communication, the high levels of supervision that most service users required proved a huge responsibility for participants, particularly those who were sole carers. Participants had firm ideas as to what was their responsibility and what belonged to A&E staff.

It was noticeable that when discussing sources of Support none of the participants made references to communication aids. This is of interest as one of the two hospitals had been supplied with pictorial aids for most treatment procedures and staff had been trained in Total Communication. It is possible that the training around learning disabilities conducted in this hospital and the package of support, served to raise staff awareness and change attitudes, rather than equip them with a specific set of skills or aids.

The source of support that was consistently mentioned in this hospital was the Liaison Nurse. Either participants made reference to how useful her support had been or they bemoaned the fact that she had not been available when they were in A&E. Even some participants from the hospital where no such Liaison Nurse existed talked about how useful such a post would be. Unanimously the post was seen as a very positive development, which immediately raised the question of exactly how the Liaison Nurse might be impacting on the service. Analysis of the results shows that the Liaison Nurse was important to the carers (and potentially via carers to service users). Her role within

this hospital is as a 'buffer' between carer and hospital staff. This mainly appears to consist of communicating carers' views (of the service users' needs) to hospital staff. There was evidence to suggest that carers find this helpful even when they themselves are present and could do this. Carers perceived there to be some added value and some suggested this was because she had a nursing qualification and was employed by the hospital and therefore her opinion may hold more validity as far as other hospital professionals were concerned. It was noted that the participants only infrequently described the Liaison Nurse's relationship or her direct involvement with the service user but mainly focused on the Liaison Nurse's support to themselves as carers in working with A&E staff. Analysis of participant comment suggests that the Liaison Nurse served two purposes. She appeared to be an intermediary in communication between carer and hospital staff and carers also described her as an agent to action. This is in keeping with several of the roles identified in Foster's (2005) 5 C's model i.e. communicator, champion, co-ordinator. There was no evidence that the Liaison Nurse within this study fulfilled a clinical carer role and the extent to which she may function as a coach (i.e. educator of staff) cannot be determined from the information gathered.

Despite some participants saying that without the Liaison Nurse present their experience might have been less positive, there were participants who felt that they had a positive experience when no Liaison Nurse was there. In the hospital where she worked it could be argued that, even in her absence, staff might be benefiting from an increased understanding and awareness through working with her on other cases. However this could not be true for the hospital where there never had been a liaison post. A question arises from this as to under what circumstances it is beneficial to have a Liaison Nurse present. This is important to consider as Liaison Nurse posts are often only 9- 5 and some, as in this case, are part time. Generally these nurses have a remit across the whole hospital and clearly therefore are a limited resource.

The significance of adequate emotional support to a service user should not be underestimated. One of the participants who arrived in hospital after the service user to find him bewildered, said in relation to overall satisfaction,

Not very [satisfied], but only because of the issue with the beds (P7 572)

which suggests that her perception of a lack of emotional support to the service user, as regards this one example, had a profound impact on her overall opinion.

There was some reference by participants to equipment, that was considered sub standard (wheelchairs) or in inadequate supply (cot sides), to support the service users. Some specific safety issues were highlighted but in addition it raised the wider issue of who should support and be responsible for the safety of service users whilst they are in hospital. From participant comment it would appear that carers themselves believe they have a role to play in this process and appear willing to do so. However there would seem to be a need for a planned contingency for each individual service user, if a carer cannot be present at all times. Fox & Wilson (1999) recommended care plans, which had been agreed by carers, for service users admitted to hospital wards. Such an approach would also have advantages in A&E.

1.4 Compliance

Another theme that emerged from this study that was linked to previous research was Compliance. In 1999 Hart's sampled population of service users identified 'Consent to Treatment' as an issue. The participants in this current study when asked about consent tended to discuss compliance and consent as if they were interchangeable. It would seem that when the participants took users to A&E, they did so because they believed urgent and necessary treatment was required and hence they did not seem to feel that consent in the A&E setting was an issue of major concern. Hart's work (1998 & 1999) with service users has focused on general hospital as oppose to A&E and there may be different expectations as regards consent between these settings. It is noticeable that researchers such as Sowney & Barr (2007), who have raised consent as being an issue within A&E, have done so following focus groups or interviews with A&E staff not carers. Despite carers not being unduly concerned about consent within an emergency setting there was evidence of some misunderstanding not only from family carers but also from participants who were professional care staff e.g. the participant who thought that a general consent to treatment form could be completed yearly by either the service user or involved professionals and used as and when necessary. Such a comment suggests a lack of understanding about the potential variable nature of consent and furthermore a lack of knowledge as regards the Mental Health Capacity Act. However some indication as to whether the service user might or might not have the capacity to

consent (although this too might vary with circumstances) and the manner in which a service user might best communicate issues of consent could be recorded.

1.5 Responsibilities

The final master theme centred on Responsibilities. It was clear from the participants' responses that they had very significant responsibilities not only to the person that they were accompanying but often to others in their care. Sometimes they had to make very swift decisions that had implications for the safety of the service user, themselves and others. The fact that participants chose to raise these issues during the interviews suggests that they were under additional pressures that may not have been obvious to hospital staff. Participants seemed to cope better when they felt that there was shared responsibility i.e. they were involved in decisions about the service users. Those that felt out of control of the situation, because staff appeared not to take their advice or did not feedback to them, struggled more. Also participants who felt too much was expected of them (e.g. had to sit for hours in a particular position to prevent a service user from falling from a wheelchair) found this challenging. Participants felt that the A&E staff had particular responsibilities e.g. in relation to medical care. On arrival at A&E, participants were not given an opportunity to clarify what their role was to be or what level of support a service user might need – A&E staff seemed to make assumptions about this. If there is insufficient time to devise a care plan, a brief discussion on admission could help clarify what carers and A&E staff see as their respective responsibilities – which might take some pressure off carers.

1.6 Themes identified in other research

Another theme identified by Hart (1998) in discussion with service users, that of 'Fear', was not so obvious within this study. Whilst some participants made general comments as to how service users react when anxious, often in relation to discussing compliance to treatment or to managing challenging behaviour, only one participant made specific reference to fear of A&E. Participants did not focus on fear as a major issue. Hart had been talking with service users directly and fear may be more significant to those experiencing it first-hand.

In a previous study (Piper & West 1998) carers had suggested that A&E staff had a poor understanding of the medication that service users might be taking and the potential interactions between these drugs and ones which might be prescribed on A&E. There was no indication from this study that any carer had similar concerns. In fact there was evidence to the contrary.

Generally participants did not make reference to medical care but there was some indication that the way in which pain is identified and treated with this service user group could be improved. For example participants suggested pictorial aids to help service users describe the severity of pain.

1.7 Summary of Clinical Implications

There are some clinical implications associated with the results of this study which include:-

- In terms of planning and evaluating services, it is important to have an awareness that the pertinent issues to carers will not necessarily be the same as those for service users and for staff. However the relevance of carer views are still significant as their experience impacts upon the service user - staff interaction.
- One A&E manager expressed concern, prior to the study, that it might highlight huge areas of deficit and result in poor staff morale. In actual fact participants had lots of positive comments to make (e.g. real appreciation of staff who behaved in a respectful and a nurturing way) and feeding these back to staff may raise their levels of confidence with this service user group. One change that participants were seeking was more feedback to them during waiting times and this is a relatively straightforward recommendation with low resource implications.
- Understanding consent is still an issue for hospital and residential staff and for carers. This has implications for improved staff training. As far as education of parents is concerned, the author has already been in contact with the Local Special Education department to explore the possibility of giving parents information about consent and capacity at the school transition review i.e. as

young people reach adulthood. Therefore parents would have an opportunity to consider this topic before they find themselves in an emergency situation.

- This research confirms that the problem of waiting for admission to a ward, described in research at other locations, is also true for the hospitals involved in this study. On a local level the findings can be used to support A&E management in their negotiations to improve this.
- Finally, a positive outcome from the study was that the researcher was then charged to facilitate the development of a Strategy for the Provision of Services for People with Learning Disability for one of the acute Trust in this study. This has been completed and some of the recommendations already implemented including the development of a Liaison Nurse post.

2.0 Reflexive Analysis

To conduct research it would seem important that an individual has:

- some knowledge and understanding of the issues - in order to be asking pertinent research questions
- a strong interest around the topic - in order to sustain the commitment that the research process will require.

However this will inevitably mean that the researcher with experience and interest, will also bring to the research preconceived views and hypotheses that will affect the methodology (the research questions asked, verbal and non-verbal interaction with the participants during interview, the prompt questions); the results (interpretation of the information gathered) and the conclusions.

It was hoped that the original research questions would yield information that would be useful in developing services. The research questions were devised not directly by people with learning disabilities themselves, but as a result of the previous research (with verbally able service users, carers and A&E staff) and the experience of the researcher (as a Learning Disability worker). Much of the literature reviewed has focused around the views of learning disability staff, carers or hospital staff. Where people with learning disabilities have been involved they have been verbally able and

have often been asked to contribute their views in wider groups alongside carers and others. This might have provided a supportive environment but also services users may have been influenced by those around them. This is not to say that the views of service users under these circumstances and of carers and Learning Disability workers are not valid, but it has to be acknowledged that the research questions have evolved from a variety of sources and not necessarily from people with learning disabilities themselves.

During the interviews, whilst it is acknowledged that researcher bias will exist, in order to avoid questioning that might lead a participant away from raising issues pertinent to them, people were invited to describe their journey through A&E. Encouraging participants to choose their own topics to discuss was considered particularly important given the interviewer's previous background of research within A&E. However, as described in the methodology, prompts were used that could not be described as a neutral. Thus participants may have been influenced in a number of different ways. Firstly if the participant required prompting, the researcher sometimes chose to ask a specific question in order to yield maximum information and to prevent the participant simply moving from one major event to another. For example if a participant were to say "Then we were asked to wait", more might be asked about this wait, as opposed to asking, "What happened next?" This was to prevent the participant assuming that the researcher wanted to hear a chronological synopsis. Thus it could be difficult to know which of the issues raised were most pertinent for the participants. Secondly during the course of the interview the participants would also have been subtly affected by the researcher's non verbal responses to what was being said e.g. nodding. Thirdly the researcher chose to ask specific questions, after participants had recounted their stories, which again will not necessarily reflect what the participants wanted to talk about. These questions were only raised in the second part of the interview and furthermore whether these issues had been spontaneously discussed was noted in the results in order to clarify what was researcher and what was participant led.

The interpretation of the results is inevitably bound up with the researcher's own belief systems and viewpoints. The very fact that the researcher has a long history within the NHS and within the field of learning disabilities is likely to strongly influence the research. Although the content of what was said by the participants has been closely analysed, different or further analysis could have been undertaken. For example one

could examine the information that resulted from prompting to see if this differed in any way from that which the participants spontaneously chose to recall. One difficulty here is that an early prompt could subsequently affect things said by the participant much later in the interview, without this being apparent. Video analysis of interviews would also identify some responses where participants may have been influenced by the non verbal actions of the researcher. Again it would not be possible necessarily to pick up on all these and this further analysis in itself would be influenced by the researcher.

In drawing together conclusions from the work, there is a likelihood that the researcher's preconceptions will add weight to particular issues raised and minimise others. This is an acknowledged process within the methodology (IPA) chosen.

3.0 Strengths & Limitations

The researcher submitted a transcript to an experienced qualitative researcher (moderator), who was not familiar with the research (nor indeed with the researcher), to verify the identification of emerging issues. This was done to explore the amount of potential bias, by the researcher, when initially viewing the data i.e. any predisposition to attribute significance to certain participant comments whilst ignoring others. There was close agreement about the issues raised suggesting that the researcher was not identifying these on the basis of preformed ideas - but obviously the moderator could only categorise what the participants had said, which in itself may have already been affected by the researcher (as described above). The interpretation of what these issues meant has come from the researcher. However after development of the emerging themes and the interpretation of these, some discussion was undertaken with a different moderator experienced in IPA to ensure that there was some rigor attached to the process.

It was considered a strength, by the researcher, that some of her preconceived ideas (recorded at the outset) were not borne out, which presumably meant that new alternative information that was being given to her by the participants, was being attended to. For example, on the basis of the literature reviewed and her experience of working within learning disabilities, the researcher anticipated higher levels of criticism,

particularly given past literature and as one A&E department had received no support from the Learning Disability services. Furthermore she believed that those wishing to put time and effort into being interviewed would do so perhaps because they had major concerns that they felt compelled to raise. Neither of these proved to be the case. This made the researcher feel that, despite researcher influence, participants did appear to have a voice.

The use of IPA in itself was considered a strength as it enabled this 'voice' to be given to a group within society who are often marginalised. It provided a framework in which to consider their experiences and avoided offering participants the chance to only comment upon that which the researcher had considered significant. As different issues arose to some of those raised in previous research this is particularly relevant.

It was also advantageous to be able to sample the experiences of participants in more than one hospital setting and although these views cannot necessarily be generalised, the research was not confined to just one A&E department.

Whilst it was a disappointment that only 2 verbal service users were interviewed and that the data gathered from the 3 non verbal service users proved inconclusive (the results from service users were not included in this thesis), results from carer participants proved valuable. Carers within this research raised different issues or had alternative interpretations about particular issues as compared with service users and hospital staff (in previous research). It also became apparent that the participant carers' relationships with A&E staff and with the Liaison Nurse were as significant to them as the relationships between the service users and these staff. Given that the majority of people with learning disabilities will present in A&E accompanied by a carer and that these carers clearly have a major role in supporting services users through the process – it would seem essential that carers' experiences and perceptions are understood.

One of the weaknesses of the work was that it is not clear whether the whole of the target population had equal access to take part in the research. There was reliance on A&E staff recognising the presence of a learning disability and it has already been established that hospital staff are not always 'disability aware'. Staff may have found it particularly difficult to identify more able adults or indeed children with learning disabilities, as one would expect a carer to accompany a child. Notices were put up

within A&E to 'catch' those people not identified by staff, but individuals may not be in the habit of reading public noticeboards, may not have had the skills to read them or may not have wished to be identified as learning disabled.

The difficulty in recruiting participants meant that whilst there were adequate numbers for the qualitative part of the study, it was not possible to conduct a comparison study using the quantitative data gathered, between service users and carers or between the two services. Not only were there too few participants for quantitative analysis, but also those carers did come forward, often did so some months after their visit to A&E - thus making it very difficult for the service users they accompanied to recall their attendance and therefore take part meaningfully. The reason for this difficulty seemed to be that A&E staff did not hand out the information packs, as had been agreed, when people were discharged from the department. Whilst the study had been agreed to by specific clinical managers (A&E consultant, A&E nurse manager) it became apparent that agreement to participation is very different to active engagement. Whilst many efforts were made to support both A&Es to become more active within the study, these efforts were ineffectual. One of the salutatory lessons from this is the importance for the researcher to have built up a relationship with frontline staff and/or to have identified a champion within the service.

There was a high degree of commonality between participants, but what the study did not identify is whether some of these themes would also be shared with the general population of A&E service users or indeed other subpopulations. Within the methodology it has already been discussed that the term 'learning disability' encompasses a group with a wide range of cognitive abilities, many different diagnoses and a diverse range of additional potential health issues or physical disabilities. It is not clear whether it is reasonable to consider people with a learning disability as a homogenous group for this work. However the rationale was that the existence of a learning disability is likely to result in some degree of communication/understanding difficulties which may produce additional challenges for staff inexperienced with these issues. There are of course other sectors of the population who might have communication/understanding difficulties in a British A&E e.g. people who have sustained serious injury and/or trauma, people whose understanding of English is poor, people with mental health problems, people with hearing impairment, those with

dementia etc. Whilst there did seem to be particular themes emerging from this research, it would be interesting to ascertain whether the same issues arise for these other groups and indeed for the population in general. For example there is some evidence from research that communication is a topic raised by A&E service users in general (Byrne & Heyman 1997).

From a clinical point of view it is not problematic if some of the themes identified in the current study also apply to a wider population- as it does not prevent changes being put in place that would better support people with learning disabilities (and perhaps others). The danger is that with a small sample group, as in this study, changes could be made that the organisation may assume to be supportive of all 'people with learning disabilities', whereas in fact they may only be applicable to some. As the minimum personal information was gathered about the service users, and that which was recorded was based on the views of carers, there was limited information about who comprised the group in this study. More detailed information such as cognitive levels, communication abilities etc could have been obtained from participants themselves or from other sources e.g. local Learning Disability Teams.

It would have been illuminating to have interviewed the A&E staff involved in the episodes of care studied. This would have determined whether staff had similar perspectives to that of carers and whether the same themes would have emerged.

4.0 Implications for Further Research

4.1 Liaison nurse posts

There is limited research around how to make most effective use of Liaison Nurses, particularly for people with learning disabilities. Investigating the effects of Learning Disability Liaison Nurses from other Trusts might help clarify this. Potential areas for consideration might include whether the post of Liaison Nurse is required for a time limited period in different hospital departments in order to effect change and whether change can be maintained irrespective of whether someone remains active in that setting; the post holder's balance between modelling to staff and staff training; to what

extent the effectiveness of the post is reliant on professional skills or the personal attributes and dynamism of the individual involved. As with any post the personal qualities of the post-holder may be hugely significant but for someone working as a single individual within many different wards and departments emphasis may need to be placed on particular personal abilities.

4.2 Views of verbal service users about A & E

There is little information available as to how verbal service users themselves perceive A&E. Some verbal service users were interviewed as part of this research (although not reported in this thesis). There is a suggestion from the literature by Hart (1998 & 1999) with verbal services users, that the issues may not be the same for service user as for carer participants. If sufficient verbal services users are sampled in future research then responses from pairs of service users and carers, describing the same episode of care, could be compared.

4.3 Views of non verbal service users

The original intention of this research was also to include non verbally able service users and to develop a technique to explore their opinions. It was then intended to use a model to compare service users' responses to those of accompanying carers to determine whether service users could distinguish between how they felt following a traumatic event as compared with how they felt about the service they received. This model makes some assumptions around shared values between service user and carer. Three service users were indeed interviewed but their responses were inconclusive and have not been included in this thesis. Retrospectively the technique employed would be better used with planned hospital appointments so that the service users could be interviewed very promptly after the experience.

CHAPTER 7

CONCLUSION

In this study the participants, who were family or professional carers accompanying a person with learning disability through Accident & Emergency, discussed their experiences. From this data the researcher identified a number of common themes: Interactions that are Valuing; Emotional Responsiveness; Support; Compliance and Responsibilities. The interactions between staff and service users and the staff and the participants were crucial in determining how participants viewed their experience of A&E. It was important to participants that these interactions were not only valuing but that staff might go beyond this and demonstrate a degree of emotional responsiveness. Carers provide high levels of support to staff and to service users and in turn they very much valued the support of a Liaison Nurse. Participants were much more positive than one might assume from previous literature but individuals still identified problems that require addressing.

REFERENCES

- Alborz A., McNally R. & Glendinning C. (2005). Access to health care for people with learning disabilities in the UK: mapping the issues and reviewing the evidence. *Journal of Health Services Research and Policy* **10**(3) 173-182
- Arcscott K., Dagnan D. & Kroese B.S. (1999). Assessing the ability of people with a learning disability to give informed consent to treatment. *Psychological Medicine* **29**(6) 1367-1375
- Atkinson D. (1997). *An auto/biographical approach to learning disability research*. Aldershot, Ashgate
- Avis M., Bond M. & Arthur A. (1997). Questioning patient satisfaction: an empirical investigation in two outpatient clinics. *Social Science Medicine* **44**(1) 85-92
- Baker R. & Hinton R. (1999). Do focus groups facilitate meaningful participation in social research? In Barbour R.S. & Kitzinger J. (eds) *Developing Focus Group Research* (pp 79-98). London, Sage
- Barr O. (1990). Knowledge of and attitudes towards people with mental handicaps: an investigation of RGN students. *Mental Handicap* **18** 109- 112
- Biersdorff K.K. (1993). Incidence of significantly altered pain experience among individuals with developmental disabilities. *American Journal on Mental Retardation* **8**(5) 619-631
- Boarder J.H. (2002). The perceptions of experienced community learning disability nurses of their roles and ways of working: an exploratory study. *Journal of Intellectual Disabilities* **6** 281

Brocki J.M. & Wearden A.J. (2006). A critical evaluation and use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health* **21**(1) 87-108

Bromley J., Emerson E. & Caine A. (1998). The development of a self report measure to assess the location and intensity of pain in people with intellectual disabilities. *Journal of Intellectual Disability Research* **42**(1) 72-80

Brown M. (2005). Emergency care for people with learning disabilities: What all nurses and midwives need to know. *Accident & Emergency Nursing* **13**(4) 224-231

Brown M. & MacArthur J. (2006). A new research agenda: improving health care in general hospitals. *Journal of Clinical Nursing* **15**(11) 1362-1370

Byrne G. & Heyman R. (1997). Understanding nurses' communication with patients in accident & emergency departments using a symbolic interactionist perspective. *Journal of Advanced Nursing* **26** 93-100

Cameron L. & Murphy J. (2002). Enabling young people with a learning disability to make choices at a time of transition. *British Journal of Learning Disabilities* **30** 105-112

Cole G., Neal J.W., Fraser W.I. & Cowie V.A. (1994). Autopsy findings in patients with mental handicap. *Journal of Intellectual Disability Research* **38** 9-26

Corbett J., Thomas C., Prior M. & Robson R. (2003). Health facilitation for people with learning disabilities. *British Journal of Community Nursing* **8**(9) 404-410

Couchman W. (1995). Using video and conversational analysis to train staff working with people with learning disabilities. *Journal of Advanced Nursing* **22** 1112-1119

Creswell J.W. (1998). *Qualitative Inquiry and Research Design: choosing among five traditions*. Thousand Oaks/ London, Sage

Cumella S. & Martin D. (2004). Secondary health care and learning disability: results of consensus development conferences. *Journal of Learning Disability* 8(1) 30-40

Cunningham C.C., Morgan P.A. & McGucken R.B. (1984). Down's Syndrome: is dissatisfaction with disclosure of diagnosis inevitable? *Developmental Medicine & Child Neurology* 26 33-39

Darbyshire P. (1993). Paving the way. *Nursing Times* 89(41) 42-44

Department of Health (1995). Health of the Nation. London, HMSO

Department of Health (1999a). Once a Day. London, HMSO

Department of Health (1999b). Facing the Facts, services for people with learning disabilities: a policy impact study of Social Care and Health Services. London, DOH publications

Department of Health (2001a). Nothing About Us Without Us. London, HMSO

Department of Health (2001b). Valuing People a new strategy for learning disability for the 21st century. London, HMSO

Department of Health NHS Executive (1998). Signposts for Success in commissioning and providing health services for people with learning disabilities. London, HMSO

Department of Health NHS Executive (1999). Doubly Disabled: Equality and disabled people in the new NHS access to services. London, HMSO

Disability Discrimination Act (1995) Part III Sections 19-21. London, HMSO

Downing A., Wilson R.C. & Cooke M.W. (2004). Which patients spend more than 4 hours in the Accident and Emergency department. *Journal of Public Health* 26(2) 172-176

- Emerson E. & Hatton C. (2007). Contribution of socioeconomic position to health inequalities of British children and adolescents with intellectual disabilities. *American Journal on Mental Retardation* **112**(2) 140–150
- Faw G.D., Davis P.K. & Peck C. (1996). Increasing self-determination: teaching people with mental retardation to evaluate residential options. *Journal of Applied Behavior Analysis* **29**(2) 173–188
- Fitzpatrick R. (1997). Patient satisfaction. In Baum A., Newman S., Weinman J., West R. & McManus C. (eds) *Cambridge Handbook of Psychology, Health and Medicine* (pp. 301-304) Cambridge, Cambridge University Press
- Foley D. & McCutcheon H. (2004). Detecting pain in people with an intellectual disability. *Accident and Emergency Nursing* **12**(4) 196-200
- Foster J. (2005). Learning disability liaison nurses in acute hospitals: is there evidence to support the development of this role? *Learning Disability Practice* **8**(4) 33-38
- Fox D. & Wilson D. (1999). Parents experiences of general hospital admission adults with learning disabilities. *Journal of Clinical Nursing* **8** 610-614
- Gill F., Stenfort Kroese B. & Rose J. (2002). General practitioners' attitudes to patients who have learning disabilities. *Psychological Medicine* **32** 1445-1455
- Glasby A. (2002). Meeting the needs of people with learning disabilities in acute care. *British Journal of Nursing* **11**(21) 1389-92
- Goodman K. (1998). Service user involvement. In Burton M. & Kellaway M. (eds) *Developing and Managing High Quality Services for People with Learning Disabilities* (pp257–269) Aldershot, Ashgate
- Gudjonsson G.H. & Clare I.C.H. (1995). The relationship between confabulation and intellectual disability, memory, interrogative suggestibility and acquiescence. *Personality & Individual Differences* **19**(3) 333- 338

Hart S.L. (1998). Learning-disabled people's experience of general hospitals. *British Journal of Nursing* 7(8) 470-477

Hart S.L. (1999). Meaningful choices: consent to treatment in general health care settings for people with learning disabilities. *Journal of Learning Disabilities for Nursing, Health and Social Care* 3(1) 20-26

Holloway I. (2005). *Qualitative Research in Healthcare*. Maidenhead UK, Open University Press

Howells G. (1986). Are the healthcare needs of mentally handicapped adults being met? *Journal of the Royal College of General Practitioners* 36 449-453

Hutton J. in Department of Health (1999). National Strategy for Learning Disability Services- announced press release. London, DoH

Jukes M. & Bollard M. (2002). Health facilitators in learning disability are important roles. *British Journal of Nursing* 11(5) 297

Kerr D., Cunningham C. & Wilkinson H. (2006). *Responding to the pain experiences of people with a learning difficulty and dementia*. Joseph Roundtree Foundation, York Publishing Services

Lancaster University (2004). *Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England*. Lancaster, Institute for Health Research

Langan J., Whitfield M. & Russell O. (1994). Paid and unpaid carers: their role in and satisfaction with primary health care for people with learning disabilities. *Health and Social Care* 2 357-365

Larkin M., Watts S. & Clifton E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Quality Research in Psychology* 3 102-120

Lindsey M., Singh K. & Perrett A. (1993). Management of learning disability in the general hospital. *British Journal of Hospital Medicine* 50(4) 182-186

Lloyd M., Preston-Shoot M., Temple B. & Wu R. (1996). Whose project is it anyway? Sharing and shaping the research and development agenda. *Disability & Society* 11(3) 301-315

Lohrmann-O'Rourke S. & Browder D.M. (1998) Empirically based methods to assess the preferences of individuals with severe disabilities *American Journal on Mental Retardation* 103(2) 146–161

Lonkila M. (1995). Grounded Theory as an emerging paradigm for computer- assisted qualitative data analysis. In Kelle U. Prein G. & Bird K. (eds) *Computer Aided Qualitative Data Analysis: Theory, Methods & Practice*. London, Sage

Lowe K. (1992). Consumer based service-what consumers think. *Journal of Mental Subnormality* 38 6 -14

Marshall S., Martin D. & Myles F. (1996). Survey of GPs' views of learning disability services. *British Journal of Nursing* 5(13) 798-804

Mencap (2007). *Death by Indifference – following up the Treat Me Right report*. London, Mencap

The Mental Capacity Act (2005) London, HMSO

Mental Health Foundation (1996). *Building Expectations – opportunities and services for people with a learning disability: Report of the Mental Health Foundation Committee of Inquiry*. London, Mental Health Foundation

McCaffrey M. & Beebe B. (1994). *Pain: Clinical manual for nursing practice*. London, Times Mirror International Publishers Limited

McConkey R. & Truesdale M. (2000). Reactions of nurses and therapists in mainstream health services to contact with people who have learning disabilities. *Journal of Advanced Nursing* **32**(1) 158-163

The National Health Service & Community Care Act (1990) London, HMSO

North Staffordshire Hospitals and Combined Health NHS Trusts (undated). Guidelines for Accident and Emergency staff when treating people with learning disabilities. *National Network for Learning Disability Nurses A2A Group, Standards & Protocols Appendix 5b*

Nurse A.D., Rohde J.R. & Farmer R.D. (1990). A study of doctors' and parents' attitudes to people with mental handicaps. *Journal of Mental Deficiency Research* **34**(2) 143-55

Nyström M., Dahlberg K. & Carlsson G. (2003). Non-caring encounters at an emergency care unit – a life-world hermeneutic analysis of an efficiency-driven organization. *International Journal of Nursing Studies* **40**(7) 761-69

Paine S. (1994). A report of the findings of a 1 year study of the waiting times among patients attending an accident and emergency department. *Accident & Emergency* **2**(3) 130-133

Patja K., Iivanainen M., Vesala H., Oksanen H. & Ruoppila I. (2000). Life expectancy of people with intellectual disability: a 35-year follow-up study. *Journal of Intellectual Disability Research* **44**(5), 591–599

Piper E. & West J. (1998). Consultation with parent carers and service users to inform strategic development of learning disability services. Unpublished report for an NHS Trust

Piper E. (1999). Not 2nd Class Citizens: how can the NHS ensure that people with a learning disability receive an equitable service in accordance with the Disability Discrimination Act? Unpublished MBA thesis, Henley Management College, Brunel University

R v Bournewood Community and Mental Health NHS Trust, ex parte L (1998)

Rimmer J. W. & Whitfield M. (1995). *Can primary health care teams and community learning disability teams collaborate to provide preventive health care for patients with learning difficulties?* Bristol, Avon Medical Audit Advisory Group

Royal College of Nursing (2006). Meeting the health needs of people with learning disabilities – guidance for nursing staff. London, RCN

Scheepers M., Kerr M., O'Hara D., Bainbridge D., Cooper S-A., Davis R., Fujiura G., Heller T., Holland A., Krahn G, Lennox N., Meaney J. & Wehmeyer M. (2005). Reducing health disparity in people with an intellectual disability: a report from Health Issues Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities. *Journal of Policy & Practice in Intellectual Disabilities* 2(3-4), 249-255.

Shanley E. & Guest C. (1995). Stigmatisation of people with learning disabilities in general hospitals. *British Journal of Nursing* 4(13) 759-761

Sinclair L., Hunter R., Hagen S., Nelson D. & Hunt J. (2006). How effective are mental health nurses in A&E departments? *Emergency Medicine Journal* 23 687-692

Slevin E. (1995). Student nurses' attitudes towards people with learning disabilities. *British Journal of Nursing* 4(13) 761-766

Slevin E. & Sines D. (1996). Attitudes of nurses in a general hospital towards people with learning disabilities: influences of contact, and graduate non-graduate status, a comparative study. *Journal of Advanced Nursing* 24 1116-1126

Smith J.A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology* **1** 39-54

Smith J.A. & Osborn M. (2003). Interpretative phenomenological analysis. In Smith (ed) *Qualitative Psychology: a practical guide to research methods*. London, Sage

Smith J.A., Flowers P. & Osborn M. (1997). Interpretative phenomenological analysis and the psychology of health and illness. In Yardley L. (ed) *Material Discourses of Health and Illness*. London, Routledge

Smith J.A., Jarman M. & Osborn M. (1999). Doing interpretative phenomenological analysis. In Murray M. & Chamberlain K. (eds) *Qualitative Health Psychology: theories & methods*. London, Sage

Sowney M. & Barr O.G. (2006). Caring for adults with intellectual disabilities: perceived challenges for nurses in accident and emergency units. *Journal of Advanced Nursing* **55**(1) 36-45

Sowney M. & Barr O. (2007). The challenges for nurses communicating with and gaining valid consent from adults with intellectual disabilities within the accident and emergency care service. *Journal of Clinical Nursing* **15** 1-9

Spiegelberg H (1959). *The Phenomenological Movement: A historical introduction*. Boston, Martinus Nijhoff

Stenfert Kroese B., Guillot A. & Atkinson V. (1998). Consumers with intellectual disabilities as service evaluators. *Journal of Applied Research in Intellectual Disabilities* **11**(2) 116-128

Tuffrey-Wijne I., Hollins S. & Curfs L. (2005). Supporting patients who have intellectual disabilities: a survey investigating staff training needs. *International Journal of Palliative Nursing* **11**(4) 182-188

Turner S. & Moss S. (1996). The health needs of adults with learning disabilities and the Health of the Nation strategy. *Journal of Intellectual Disability Research* **40**(5) 438-450

Williamson A. & Johnson J. (2004). Improving services for people with learning disabilities. *Nursing Standard* **18**(24) 43- 51

Wilson D. & Haire A. (1990). Health care screening for people with mental handicap living in the community. *British Medical Journal* **301** 1379-1381

Wishart J.G. & Johnston F.H. (1990). The effects of experience on attribution of a stereotyped personality to children with Down's syndrome. *Journal of Mental Deficiency Research* **34**(5) 409-420

Yuker H. E. & Block J. R. (1986). *Research with the Attitudes Towards Disabled Persons scales (ATDP) 1960-1985*. New York, Hofstra University Press

APPENDIX 1

Letter from Ethics Committee



Cornwall Local Research Ethics Committee (LREC)

Knowledge Spa
Royal Cornwall Hospitals NHS Trust
Truro, Cornwall TR1 3HD
Tel: 01872 256422
Fax: 01872 256422

E-mail carmen.thomas@rcht.cornwall.nhs.uk

16 February 2005

Mrs Liz Piper
Consultant Clinical Psychologist
Cornwall Partnership Trust
Chy Govenek
Threemilestone Industrial Estate
Truro TR4 9LD

Dear Mrs Piper

Full title of study: *Investigating the Experience of People with Learning Disabilities and their Carers in Accident & Emergency including evaluating a package of support and exploring whether people with learning disabilities (verbal and non-verbal) are capable service evaluators.*

REC reference number: 05/Q2101/5

Thank you for forwarding an example of the notice (Version 1) to be displayed in the Accident and Emergency Department, RCHT, in response to the Committee's request for further information on the above research.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

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

The favourable opinion applies to the research sites listed on the attached form. Confirmation of approval for other sites listed in the application will be issued as soon as local assessors have confirmed that they have no objection.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

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

Document Type:	Version:	Dated:	Date Received:
Application	1	18/01/2005	19/01/2005

Investigator CV		18/01/2005	19/01/2005
Protocol	1	19/01/2005	19/01/2005
Summary/Synopsis	1	19/01/2005	19/01/2005
Interview Schedules/Topic Guides	1	19/01/2005	19/01/2005
Copy of Questionnaire	1	19/01/2005	19/01/2005
Participant Information Sheet	1	19/01/2005	19/01/2005
Participant Consent Form	1	19/01/2005	19/01/2005
Response to Request for Further Information	1	15/02/2005	15/02/2005

Management approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final management approval from the R&D Department for the relevant NHS care organisation.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

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

05/Q2101/5 **Please quote this number on all correspondence**

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

Yours sincerely,

Dr Maurice Wooldridge
Chair

Enclosures *List of names and professions of members who were present at the meeting and those who submitted written comments*

Standard approval conditions

Site approval form (SF1)

APPENDIX 2

Introductory letter to potential participants

Dear Service User/ Parent/ Carer,

I work for Learning Disabilities Services and are interested in the experiences of people with Learning Disabilities using A&E across X & Y area.

By Learning Disability I mean people who have global learning difficulties that effect day-to-day living. This learning difficulty will have been present from childhood.

The attached information sheet tells you about the study. Please fill in the slip below and return in the stamped addressed envelope if you would like me to contact you, so you can let me know your views.

Yours faithfully,

Liz Piper
Consultant Clinical Psychologist

Name of Service User

.....

Name of Carer(s)

.....

Relationship to service user

.....

Contact address for carer(s)

.....

.....

.....

Contact telephone number

.....

We/ I should like one of the above workers to contact us/ me

Signature of

carer(s).....

APPENDIX 3a

Information sheet for participants

Investigating the Experiences of People with learning disabilities in Accident and Emergency.

We want to know what you think about Accident & Emergency at the hospital.



We would like to ask you some questions. ? This may take an hour.



We can meet with you at home or a day centre. You can bring someone with you if you want.



If you don't want to talk with us that's OK.

If you would like us to listen to what you think, you or your carer can let us know.

Your comments will help us make services better for you.



APPENDIX 3b

Information sheet for participants

Investigating the Experiences of People with Learning Disabilities in Accident and Emergency

You are being invited to take part in a research study that is looking into the experiences of people with learning disability in Accident and Emergency (A & E). Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

In the past we have asked carers in the South West what they thought about NHS services for people with a learning disability. Following on from this work, we should like to ask carers/ parents about their recent experiences in A&E. *Wherever possible we should also like to interview service users themselves.

This study involves an interview that should take no more than an hour or so. Your involvement is entirely voluntary. If you do decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision to not take part, will not affect the standard of care you receive in the future or will not restrict your access to any services. If you do decide to take part your involvement is entirely confidential.

The results of this research will hopefully be published and should you wish a summary of the results to be sent to you then you may request so. Should the research be published you would not be identified in any way.

This research was also subjected to an NHS ethics committee review.

** This sentence was only included in Service Y*

APPENDIX 4

CONSENT FORM

Centre Number:

Study Number:

Patient Identification Number for this trial:

Title of Project: **Investigating the Experiences of People with LD in A&E.**

Name of Researcher: **Chief Investigator:**

Please initial box

- 1. I have read and understand the information sheet dated(version)

- 2. I understand that my participation is voluntary and that I can stop at any time, without giving any reason, without my medical care or legal rights being affected.

- 3. I understand that sections of any of my medical notes may be looked at by responsible individuals from the Cornwall Partnership Trust (CPT) or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.

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

Name of Patient

Date & Signature

Name of Person giving consent
(if different from patient)

Date & Signature

Researcher

Date & Signature

APPENDIX 5

INTERVIEW SCHEDULES

Introduce Self

Explain research drawing participants' attention to the information sheet which they have already been sent, running through if necessary.

Remind participants of the fact the study has ethics committee approval, that the data will be presented anonymously (including all names changed in any quotes used) and that the participant can choose to stop the interview at any time.

Explain rationale and ask permission for using an audiotape.

Ask participant if they are willing to sign consent form and then complete with them.

Begin the interview

Part 1 of interview

You used the A&E Department can you tell me when that was?

I should like you to describe to me/ tell me what happened from the time that you arrived/got there to when you left A&E (either to go home or to go onto a ward)?

The participant is encouraged to describe the experience in his or her own words. Prompts may be given if a participant falters in their account such as "you said that were waiting after the first nurse saw you, what happened during that time". Questions may be asked to clarify what the participants mean, "you said that the doctor was kind, what makes you say that?"

When the participant has finished describing the event the following questions on part 2 of the schedule may be asked to prompt further information. (The participant may have already supplied some of the information and this needs to be acknowledged). Not all the questions may be asked depending on the answers already supplied.

Part 2

Communication

C1) *With whom did staff communicate? (note, this may be different for different staff members)*

Prompts - *With you as carer, with the service user, with both of you?*

Was this okay for you, for your son/daughter/service user/client?

C2) *If applicable What methods did staff use to communicate directly with your daughter/son/ client?*

Prompts - *Ordinary non modified speech*

Simplified speech

Gestures

Signing

Photocards

Drawings done at the time

Demonstration

Others e.g. books, facial expressions

and if used were they helpful?

C3) *Was sufficient time given for explanation for you? for the client?*

C4) *Overall how satisfied were you with how staff communicated with your son/daughter/client?*

Very satisfied

Fairly

Not very

Not at all

C5) *How might we improve the service?*

Waiting Time

W1) *Approximately how long do you think you were in Accident and Emergency overall?*

W2) *Approximately how much time was spent in waiting to first see a worker?*

W3) *Do you think you waited Longer/Same time/Less Time /Don't know than others?*

If applicable If longer/less time, why do you think this was?

W4) *Overall how satisfied were you that your son/daughter/client experienced similar waiting times to others attending A&E?*

Very satisfied

Fairly

Not very

Not at all

W5) *How might we improve the service?*

Pain Relief

P1) *Was your son/daughter/client experiencing pain or discomfort as a result of the injury/illness for which you attended A&E?*

P2) *How did the staff check whether their patient was in pain?*

Was this method of checking adequate?

P3) *How did the staff check where the pain was located?*

Was this method of checking adequate?

P4) *How did the staff check the severity of the pain (resulting from either the injury or illness or from any medical procedures required)?*

Was this method of checking adequate?

P5) *Did you feel that your son/daughter/client should be given pain relief?*

Was he/she given any pain relief for the injury/illness or during any medical procedure?

If applicable, why do you think this might have been?

P6) *Overall how satisfied were you with the way in which your son's/daughter's/client's pain was managed A&E?*

Very satisfied

Fairly

Not very

Not at all

P7) How might we improve the service?

Consent

Ct1) At any time during your visit was your son/daughter/client asked to give verbal or written consent to any medical treatment?

If yes:-

a) How was the consent obtained?

b) Did your son/daughter/client understand what was being asked of him/her?

Ct2) During your visit were you asked to give verbal or written consent to any medical treatment for your son/daughter/client?

Ct3) Overall how satisfied were you with the way in which consent for treatment was asked for?

Very satisfied Fairly Not very Not at all

Ct4) How might we improve the service?

Overall

Ov1) How satisfied were you with your or your son's/daughter's/client's overall experience at A&E?

Very satisfied Fairly Not very Not at all

Ov2) How might we improve the service?