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EFFECTIVE COMMUNICATION WITH PEOPLE WITH  
LEARNING DISABILITIES WITH EPILEPSY AND THEIR  
CARERS

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A thesis submitted in partial fulfilment of the  
requirements of  
Robert Gordon University for  
the degree of Doctor of Philosophy

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of Scotland Managed Clinical Network for Epilepsy

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## Abstract

People with learning disabilities constitute about 2% of the general population. Epilepsy is more prevalent among people with learning disabilities compared with the general population. Effective communication is central to the management of people with learning disabilities and epilepsy. It has both therapeutic and health promotion functions including psycho-social benefits to the individual and their carers. Carers play vital roles in supporting individuals who live in the community to manage their conditions and the need for effective communication between service users and health care professionals is crucially important. Effective communication may not only lead to improved quality of life but may reduce mortality through the promotion of better understanding of seizures and encouraging efficient use of medication.

Despite this communication regarding community-based adults with mild learning disabilities has not been fully studied, in particular the service users' views and experiences regarding communication has been a neglected area. Yet, the service users' views may be the best source for the definition of effective communication. This study was triggered by the paucity of research that investigated service users' views and experiences regarding communication. Furthermore, numerous health policies have been formulated that emphasise the involvement of patients as consumers in the provision and delivery of health services. This study is purported to bridge this communication gap by offering service users a rare opportunity for them to express their views and experiences regarding communication to inform health policies and clinical practice.

This study adopts a naturalistic qualitative approach and employs in-depth semi-structured interviews to solicit service users' and their carers' views and experiences regarding communication. The interviews also investigated service users' and carers' perspectives in

regard to communication with health care professionals'. Carer communication diaries were used to supplement the carers' interview data and also to endorse the credibility of the study findings.

Six main findings emerged from this study that described service users' and carers' views and experiences regarding communication: communication needs and expectations; 'engagement' as a predictor of effective communication; strategies of communication; facilitating factors of communication; methods of communication; barriers to communication.

This study suggests that effective communication with people with learning disabilities and epilepsy requires a reflective model that incorporates self-assessment and awareness of the individual's communication needs and expectations. The model and recommendations that emerged from this study may be a useful resource for health and social care professionals.

**Keywords:** Communication, learning disabilities, epilepsy, carers, health care professionals.

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## Chapter 1: Introduction

In the UK people with learning disabilities form a sizeable minority within the general population (Cooper et al., 2004). It is estimated that people with learning disabilities constitute about 2% of the general population (Cooper et al., 2004) and this translates to about 7-30 people with mild to severe learning disabilities in each general practice across the UK (Emerson, 2001). Epilepsy is one of the most common enduring neurological conditions affecting people with learning disabilities. Estimates are that up to a third of all people with learning disabilities have epilepsy and up to a quarter of all people with epilepsy have learning disabilities (Lhatoo and Sander, 2001). Further estimates are that epilepsy is 20-25 times more common among people with learning disabilities compared with the general population (Whitten and Griffiths, 2007). It is estimated that people with learning disabilities are about 20-30 times more likely to have seizures compared with the general population (Moran et al., 2004; Scheepers et al., 2004). Also, the percentage of people with learning disabilities who achieve seizure freedom is said to be lower than for the general epilepsy population (Kelly et al., 2004).

Mortality rates in people with learning disabilities and epilepsy are said to be five times higher compared with the learning disabilities population overall (Forsgren et al., 1996, 2005a, 2005b). Further estimates show that about 30% of epilepsy related deaths occur among people with learning disabilities (Wilcox and Kerr, 2006). Epilepsy is known to be a strong predictor of mortality (Loughran and O'Brien, 2001). In particular, sudden unexpected death is said to be about 24 times higher in people with epilepsy compared with the general population (Ficker, 2000; Ficker et al., 1998). This will require multidisciplinary communication involving service users, carers and health care professionals to manage epilepsy and improve quality of life.



It is argued that epilepsy management and related issues such as side effects and non-compliance can be compounded by communication difficulties (Kerr, 2001). However, communication involving people with learning disabilities has been ill studied; in particular, service users' views and perspectives regarding communication have received little attention.

Communication has been variously defined but is generally referred to as a process where information, meanings and feelings are shared through the exchange of verbal and non-verbal messages (Brooke and Heath 1993 in: Berry, 2007). It takes into account the communicators, the message or content of the communication, the medium through which the message is conveyed, the communication channels and the context in which the interactions occur (Hargie and Dickson, 2004). This focus of communication reflects the definition put forward by Rogers and Kincaid 'as a process in which participants create and share information, feelings and experiences with one another in order to reach a mutual understanding' (Rogers and Kincaid, 1981). The term "effective communication" has been widely applied in health care communication (DiMatteo, 2004; Fallowfield and Jenkins, 1999; Weider et al., 2005). Effective communication is generally acknowledged as central to effective health management (Berry, 2007). However, it remains unclear how the 'effectiveness' is determined or defined in a communication encounter and more importantly how this could be maximised (van der Gaag, 1998). It is argued that the 'effectiveness' is dependent upon the success of the communication at achieving a set goal or task (Hargie and Dickson, 2004). Berry forwarded that on most occasions, effective communication depends on the appropriate use of both verbal and non-verbal channels (Berry, 2007). Moreover, interpersonal communication involves at least two participants and the effectiveness of the communication is a shared responsibility between the communicating partners. It is further claimed that effective communication involves the following; an intention to share, a desire

to reach common understanding, active listening by the receiver, understanding by all parties, the influences of background culture, the commitment to use accessible language and the mutual willingness to ensure understanding (Higgs et al., 2005).

In this study, communication occurs between: Service users; carers and healthcare professionals. Therefore, the individuals' inputs and views may serve to indicate key determinants of the effectiveness and ineffectiveness of communication. To identify or ensure effective communication, there is a need for holism that takes into account the individuals' views and perspectives regarding communication. Communication is a central human process that enables individual and collective adaptation to health risks at many different levels (Kreps, 2003). However, communication with people with learning disabilities has not been fully investigated; in particular, the service users' views regarding communication have not been solicited.

Furthermore, the presence of epilepsy may introduce additional communication needs for the individual. Effective communication may be crucial to the management of people with learning disabilities and epilepsy because it has therapeutic effects for the service user (Travaline et al., 2005) and the health promotion functions including psycho-social benefits (Rimmer, 1999). Whereas effective communication is associated with beneficial effects, ineffective communication may lead to a range of negative outcomes e.g. failures to engage with health services or follow recommended treatment regimes (Berry, 2007). People with learning disabilities and epilepsy may be receiving medications to control seizures. However, it is claimed that people with learning disabilities are more susceptible to unidentified side effects (Hannah and Brodie, 1998) and are more vulnerable to neurotoxic effects caused by some antiepileptic medications (Alvarez et al., 1998). Overall, non-adherence to treatment is reported to be higher among people with learning disabilities compared with the general population and this could be

due to cognitive and communication impairments (Whitten and Griffiths, 2007).

Effective communication is reported to be associated with positive health outcomes by promoting adherence to medications (Martin et al., 2005; Travaline et al., 2005; Weider et al., 2005). Furthermore, there is a growing interest in health promotion for people with learning disabilities with the goal of reducing secondary conditions; for example, obesity, hypertension and pressure sores including the promotion of independence, the provision of opportunities for leisure and enjoyment to enhance quality of life by reducing environmental factors that act as barriers to good health (Rimmer, 1999). Effective communication involving service users, carers and healthcare professionals is crucially important in this regard.

Carers play vital roles in supporting individuals with learning disabilities to manage their conditions and the need for effective communication between service users and carers is vitally important. Effective communication may not only improve quality of life but may reduce mortality through the promotion of better understanding of seizures and encouraging concordance with medication.

Several studies have investigated communication involving people with learning disabilities (Graves, 2007; McConkey et al., 1999; Ziviani et al., 2004) as discussed in section 2.8.1. However, there is no study that investigated the views and experiences of people with learning disabilities and epilepsy regarding communication at the time of writing this thesis. Previous research focused on carers' and health and social care professionals' views, and the development of their communication skills (Kyle et al., 2010; Purcell et al., 2000; van der Gaag, 1998). This is to the neglect of the service users' views and experiences regarding communication.

In addition, some of these studies regarding people with learning disabilities are institutionally-based involving people with severe to profound learning disabilities (Bradshaw, 2001; Jones, 2000; Purcell et al., 1999) but little is known regarding community-based individuals who may have different communication needs and expectations. The findings that community-based individuals with epilepsy are less likely to be diagnosed (Wilcox and Kerr, 2006) and have poorer seizure control (Branford et al., 1998a, 1998b; Huber et al., 2005, 2007; Huber and Seidel, 2006) demonstrate the need for further investigation in this area. Effective communication can inform epilepsy diagnosis, encourage adherence to medication and prevent seizures (Kreps, 2003)

To a significant extent, other studies (McConkey et al., 1999; Purcell et al., 2000) adopt quantitative approaches and employ observational methods by means of video-recording and quantifying the frequencies of social care staff use of verbal and non-verbal forms of communication with service users. However, it is claimed that quantitative studies are not able to take full account of the multiple interactions that take place in a social setting (Cronbach, 1975). Instead, qualitative research seeks to study social interactions and understand service users' and carers' perspectives regarding communication, provide insight into what their views and experiences are regarding communication with health care professionals (Rowan and Huston, 1997). However, the service users' views and experiences of communication remain unsolicited. This is despite numerous research findings which indicate that some people with learning disabilities when given the right support and facilitation are more than capable of communicating and expressing their views regarding health issues (Young and Chesson, 2006, 2007). Yet there is a paucity of research that investigates the views and experiences of people with learning disabilities regarding communication, for example by the use of qualitative interviews. This study is purported to bridge this communication gap by offering people with learning

disabilities and carers this rare opportunity for them to express their views and experiences regarding communication to enable a holistic understanding of communication based on the consumers' perspectives.

The focus of this study reflects health policies forwarded across the UK emphasising the involvement of service users as consumers in the provision and delivery of health service. For example, *Partnership for Care* (Scottish Executive, 2003b) which builds on the foundations laid by *Our National Health: A plan for action a plan for change* (Scottish Executive, 2000a). The former reinforces the need for involving patients and the community in service planning and delivery. *Partnership for Care* advocates for health improvement, quality standards and redesign, advocacy and listening to patients. *Building a Health Service fit for the Future* (Scottish Executive, 2005) also places emphasis on reducing health inequalities, involving the public and patients regarding how health services are provided.

The Mental Health (Care and Treatment) (Scotland) Act 2003 for 'mental disorder' including people with learning disabilities also places emphasis on service users participation, non-discrimination, equality, respect for diversity, reciprocity and respect for carers, informal care and the use of least restrictive alternatives in the delivery of health services (Scottish Executive, 2003a). This reflects agendas set in earlier government papers specifically relating to people with learning disabilities. For example, *Valuing People: A New strategy for learning disability for the 21<sup>st</sup> century* (Department of Health, 2001) and 'The Same as You?' (Scottish Executive, 2000b), a review of services for people with learning disabilities, both focus on the importance of inclusion, independence, choice and involving the views of people with learning disabilities in the provision of health services. People with learning disabilities have a right to lead an independent life like anybody else, with equal opportunities and responsibilities and to be treated with dignity and respect (Department of Health, 2001). 'The

*Same as You?* (Scottish Executive, 2000b) also stresses the importance of advocacy to enable people with learning disabilities to have a say and to be able to make informed decisions regarding the services they receive. The most recent document in England: *Valuing people now: A new three-year strategy for people with learning disabilities* (Department of Health, 2009) which builds on the previous policy recognises that good health for people with learning disabilities is a key priority in the provision and delivery of health services across England. Although these policies appeared to be congruent with service users' expectations it is unclear how these reflect clinical practice.

The role of carers' has also received government recognition as contained in the carers' strategy: *Carers at the heart of 21<sup>st</sup> century families and communities: A caring system on your side, a life of your own* (Department of Health, 2008). It seeks among other things to value carers as partners who need to have access to support in their caring roles. In particular, epilepsy is an enduring condition and may not only be impacting on the quality of life of the service user but also the carer, especially family carers. The provision of sufficient information for carers regarding epilepsy may alleviate distress and also facilitate communication with the service user and health care professionals. Furthermore, it recognises that positive shift to independent living in communities will continue to require significant contributions from carers in supporting people who have learning disabilities and also epilepsy to manage their conditions (Department of Health, 2008).

Effective communication with service users will contribute significantly to the provision of effective care for service users. However, for communication to be effective, it needs to take into consideration the service users' views and experiences regarding communication. This may lead to the identification of effective ways of facilitating communication to enhance quality of life.

## 1.1 Study rationale

The fundamental reason for this study is to understand how people with learning disabilities communicate, their experiences, views and perspectives regarding communication with carers and health care professionals. This study importantly focuses on the numerous health policies forwarded in relation to consumer involvement particularly with respect to people with learning disabilities and the delivery of health services. The design of this study will allow the researcher to make sense of the interplay between government policies and frontline staff regarding how social care professionals' practices reflect relevant health policies. Communication, in particular the voice of the service user, forms the backbone of any meaningful involvement. If service users are to have any involvement in the management of their own care as stipulated in the government agenda, one way of implementing this is by actively involving service users as stakeholders through communication. This approach will enable service users to adopt a more consumerist approach regarding the services they receive if they so desire.

Relevant questions in this study are: To what extent are service users involved in the management of their care? What are their views regarding communication with their carers and health and social care professionals regarding epilepsy and related issues? How do carers view their communication with service users and health and social care professionals? Carers provide an invaluable role in supporting people with learning disabilities and epilepsy in managing their conditions. Therefore, there is a need for carers to have basic knowledge and information regarding epilepsy to facilitate communication and also to respond to service users' needs, for example, in the event of an emergency such as seizures. It is anticipated that the findings from this study will not only lead to the identification of effective communication approaches involving people with learning disabilities and their carers, but will also offer the

opportunity for participants to share their lived experiences regarding epilepsy. This may lead to improved quality of life for both the service user and the carer.

*Carers* as used in the context of this study refer to: 1. family carers (for example husband and wife or close relatives) and 2. Care workers (for example lay or professional carers). Where appropriate, specific data referring to either of them will be indicated.

## 1.2 Study aim and Objectives

The main aim of this project is to identify effective methods of communication for people with learning disabilities and epilepsy and their carers, regarding epilepsy and related issues.

The study objectives are to:

1. investigate how people with learning disabilities and epilepsy communicate with carers and health and social care professionals regarding epilepsy and related issues;
2. explore the strategies used by carers to communicate with people with learning disabilities regarding epilepsy;
3. determine carers' perceptions of how people with learning disabilities and epilepsy communicate with health and social care professionals;
4. explore communication methods described by people with learning disabilities and their carers;
5. make recommendations on strategies which could be employed by people with learning disabilities, carers and health and social care professionals to facilitate communication, regarding key issues such as seizure management and adherence to medication;

### *1.2.1 Outline of the thesis*

This thesis is structured into seven chapters. The first chapter introduces the thesis. The literature review is presented in chapter two. This includes critical appraisal of the definitions of learning



disabilities and epilepsy, the epidemiology of learning disabilities and epilepsy with a focus on synthesising issues that relate to communication. The last section of this chapter is a review of research regarding communication involving people with learning disabilities to inform the need for this study. Chapter three gives an overview of research paradigms involving people with learning disabilities and the methodology and philosophical underpinning utilised in this study.

Chapter four focuses on data analysis for both the interviews and diaries data. The overall findings of the study are presented in chapter five. Chapter six discusses the findings of the study and the implications of the study findings in particular, for policies, clinical practice and for education. It does this by drawing upon existing literature, policies and philosophies thus, highlighting the significance of this study. Finally, chapter seven concludes the study by pulling together all the main findings that emerged in relation to the study objectives. This chapter also discusses limitations or reservations relating to the study to support any interpretations of the study findings; the study's contribution to knowledge; and recommendations for policy, clinical practice, education and future research.

## Chapter 2: Literature Review

### 2.1 Introduction

The literature review presented here underpins the study aim and objectives. It describes the search strategy. The inclusion and exclusion criteria adopted and how papers were selected. Following this is a critical appraisal of the existing literature that underpins the study objectives with particular references to communication highlighting gaps in the literature and the need for this study. For an outline of the literature review see section 2.1.3 below.

#### *2.1.1 Literature search strategy*

*Identification of key words:* Keywords for this study were identified using various strategies. First; terms that define the study focus for example, learning disabilities, epilepsy, communication with health and social care professionals e.g. doctors, physicians and nurses were noted. Second; terms that are closely related and sometimes used interchangeably in the literature were also identified. For example, terms such as seizures, 'fits' and 'absence' were classified under epilepsy. A similar strategy was applied to learning disabilities to reflect mental retardation, intellectual disabilities, learning difficulties, mental handicap and developmental disabilities. Third, a search was performed in the databases using each of these terms. The results were read and the search run again using different or alternative terms.

Papers for possible inclusion were identified by combining *free text* keywords in the electronic databases. The databases used include: Medline; CINAHL; PsycINFO and ASSIANET. Thesaurus terms such as MeSH were not evaluated. An important technique used was a combined search strategy using the Boolean operators (AND/OR) for example, to combine key words and search results for communication, learning disabilities and epilepsy. Author and

bibliographic citations searches were also performed. Also, relevant hard copy journals such as British Journal of Learning Disabilities, and key texts (for example, Lincoln and Guba 1985; Ritchie and Spencer, 2003) were also followed up and hand searching of relevant published papers and relevant chapters also took place. The literature was updated on a regular basis.

*Inclusion criteria:* The databases used include: Medline 1994-2010; CINAHL 1994-2010; PsycINFO 1994-2010 and ASSIANET 1994-2010. The search was confined to English language reports. Papers for inclusion were limited to those relating to learning disabilities, epilepsy, and communication and also the involvement of carers and health and social care professionals.

The focus of this study is on learning disabilities, although there are other groups of people who experience communication difficulties expressing themselves and also understanding others, for example, people with stroke, brain tumour, head injury and aphasia. Literature reporting research on such groups was not reviewed.

*Exclusion criteria:* Duplicates of references and papers reporting similar studies were identified and removed (i.e. they were included but only once). Papers based mainly on the mechanisms of actions of anti-epileptic drugs (largely of pharmacological nature) were also excluded, together with those primarily concerned with genetic or biological aspects of learning disabilities and epilepsy.

*Selection of papers:* All abstracts were read and relevant papers located within the university and NHS e-library. Papers not available were obtained through inter-library loans. Titles and abstracts of the selected papers were entered into Reference Manager Software.

### *2.1.2 Nature of the selected papers*

Following reading of the papers the following broad classifications were applied:

- definitions and classification of learning disabilities and epilepsy
- the epidemiology of learning disabilities and epilepsy
- management and treatment of epilepsy
- communication involving people with learning disabilities and/or epilepsy and their carers.

The bulk of the literature reviewed related to the epidemiology of learning disabilities and epilepsy. This constituted the most researched aspect of learning disabilities and epilepsy, accounting for approximately 85% of about 800 published papers selected for review. Relevant papers relating to communication accounted for a small percentage (approximately 10%). The majority of these papers selected relate to the UK population reflecting the cultural-specific nature of communication and the distinctive characteristics of service provision. Selected papers from Scandinavian countries, Australia and USA were also included where necessary.

### *2.1.3 Outline of the literature review*

The literature review is grouped into three main sections. Section 2.2 focuses on the epidemiology of learning disabilities; this includes the definitions of learning disabilities, incidence/prevalence; in particular, syndromes mostly associated with epilepsy, co-morbidities, life expectancy and mortalities. Section 2.5 discusses the epidemiology of epilepsy; this includes definitions and classifications of epilepsy, prevalence, mortality e.g. sudden unexpected death in epilepsy (SUDEP) and management of epilepsy. Finally, Section 2.7 focuses centrally on communication where it appraises published research regarding communication involving people with learning disabilities and epilepsy.

## 2.2 Epidemiology of learning disabilities

### *2.2.1 Defining learning disabilities*

The term learning disabilities is relatively new in Britain (Emerson, 2001). It emerged as a result of social and political changes requiring an all inclusive and acceptable term for people who were otherwise referred to by negative terms (Auslander and Gold, 1999) such as 'idiot', 'moron', 'imbecile' and 'cretin' (Gates, 2003). In recent literature the term "learning disabilities" is used synonymously with "mental retardation" or "intellectual disabilities" and this will be applied in this study.

Definitions of learning disabilities have been debated endlessly over the years with no apparent resolution (Siegel, 1989, 1999, 2003). To date, there is no agreed definition for learning disabilities. Definitions are mostly operational and vary among different authorities (Kavale and Forness, 2000). In general, definitions relate largely to three criteria: Intelligence Quotient (IQ), social functioning and the extent to which people with learning disabilities are in contact with services (O'Brien, 2001, 2003). However, all three approaches have their strengths and limitations (O'Brien, 2001). In particular, much of the criticism has been centred on the use of IQ in the definition and diagnosis of learning disabilities.

#### *IQ definition*

Intelligence testing alone for the identification of people with learning disabilities has been widely applied (O'Brien, 2001). The International Classification of Diseases (ICD10) and Related Health Problems places learning disabilities in terms of IQ with a cut-off score of 70 and identifies the subgroups of mild (50-69); moderate (35-49); severe (20-34); and profound <20. These thresholds relate to people with a minimum age of 18 years. However, employing IQ alone as the basis of defining learning disabilities has received wide-spread criticism (O'Brien, 2001; Siegel, 1989, 1999, 2003; Whitaker, 2004). Some

schools of thought consider IQ as irrelevant to the definition of learning disabilities and call for it to be abandoned and focus attention instead, on early identification, intervention and remediation (Siegel, 2003). It is argued that using IQ in the diagnosis of learning disabilities presents more problems than it solves (Whitaker, 2004). For example, one of the main arguments presented against IQ tests is that for example, the Wechsler test is comprised of three IQ scores (performance, verbal and full scale) but there is no clarity as to which of these scores should be applied (Siegel, 2003). Furthermore, it is argued that in the vast majority of cases, it is not relevant to employ a test to determine learning disabilities. If the person can engage in a conversation, understand and undertake the test then it is quite appropriate to assume that the individual has enough basic literacy (Siegel, 2003).

The IQ score relies on a measure of discrepancy between the individual's actual achievement and their measured potentials, in other words those individuals who perform significantly below average when compared with their age cohorts (Kavale and Forness, 2000; Siegel, 1999). When the difference is significant then the person is said to have learning disabilities (Siegel, 1999, 2003). However, this discrepancy definition is found to be unhelpful in the diagnosis of learning disabilities because any number within the IQ measure could be used to 'define' expected achievement and an even larger number can be chosen to 'define' actual achievement (Kavale and Forness, 2000). It is further argued that discrepancy in itself is a vague and hypothetical concept that requires its own definition (Kavale and Forness, 2000). Moreover, it has been proven that performance varies according to the individual mood, motivation and fatigue. While such tests may indicate significant ability to learn or a degree of literacy, they are largely designed to suit western cultures with subsequently significant implications for interpretation (Bell and Sander, 2001; O'Brien, 2001, 2003). Proponents of this view further question the claim that a low score or series of low scores imply an underlying lack

of ability and not for example, a lack of interest or motivation to undertake the tests (O'Brien, 2004; Siegel, 1999, 2003).

The notion that differences between verbal and performance scores indicate learning disabilities have also been disputed as it does not provide useful diagnosis. This is because the findings cannot be generalised (O'Brien, 2001, 2004). It is claimed that many people with learning disabilities do not show any discrepancy whilst others with normal achievement do demonstrate some level of discrepancy (Siegel, 1989, 1999, 2003). Instead, factors other than test scores such as environmental and gender factors should be considered when conceptualising learning disabilities (Molfese et al., 2001).

Furthermore, critics of the use of IQ tests claimed it discriminates against children from lower economic background (Siegel, 1999, 2003). IQ scores are found to correlate significantly with socioeconomic factors (Lawlor et al., 2005; Turkheimer et al., 2003) and individuals from poor economic backgrounds are likely to demonstrate low IQ scores probably due to lack of experience with the vocabulary and knowledge measured by the IQ test compared to cohorts with higher economic status (Siegel, 1989, 1999, 2003). The other shortcomings of the IQ measures relate to inaccuracies with the measurements. For example, it is claimed that the Wechsler test of intelligence (Wechsler, 1991, 1997) which is mostly applied in the UK does not measure within an accuracy of 1 IQ point but is usually considered to be about 95% (3-5 points) accurate (Whitaker, 2004).

Secondly, it has been reported that the IQ of the general population appears to be increasing (Flynn, 2000). Therefore, tests that were standardised decades ago now produce an average IQ greater than 100 and so put less than 2.3% of the general population with an IQ lower than 70 (Flynn, 2000). This raises questions whether IQ level should be defined as that below 70 on a test that was standardised several years ago, or as an IQ that corresponds to two standard

deviations below the average for the present population (Whitaker, 2004). For example, (Birch et al in: Whitaker, 2004) found that 2.74% of children aged 8-10 years old in Aberdeen had an IQ below 75 but this may vary significantly from today's population. According to critics, to employ intelligence testing for the identification of low IQ groups based on a statistically derived cut-off point is subjective and largely unhelpful (O'Brien, 2001, 2003).

The psychometric traditions of intelligence have been widely contested and populated by theories. For example, 'fluid' and 'crystallised' (Gf-Gc) theory of intelligence (Cattell, 1963 in: Johnson et al, 2005). This theory made significant contribution to the understanding of 'fluid' (Gf) and 'crystallised' (Gc) intelligence. It is argued that 'fluid' (Gf) intelligence reflects the ability to solve problems independent of prior experiences and that learned knowledge and skills are of little value. This is claimed to be suitably measured by tests which are not dependent on scholastic or cultural content such as figural or verbal tasks that rely on the relationship among common and familiar words. On the other hand, 'crystallised' (Gc) ability reflects consolidated knowledge acquired through education, access to cultural information and experience. According to the Gf-Gc theory, crystalline intelligence reflects an individual's fluid intelligence as well as access to learning experiences (Johnson and Bouchard, 2005).

Furthermore, the focus on psychometric examination, in particular, the application of standardised intelligence test with the emphasis on linguistic symbolization and logical-mathematical symbolization, has been contested by the theory of Multiple Intelligence (MI) (Gardner and Hatch, 1989). Gardner and Hatch argued that although psychometric tests are important in scholastic settings, other varieties of symbol use are common and feature prominently in human cognitive capacities within and outside educational settings (Gardner and Hatch, 1989). They referred to intelligence as the ability to solve



problems or to fashion products that are valued in one or more cultural settings. According to the MI theory humans exhibit seven forms of intelligence e.g. linguistic, logical-mathematical, musical, spatial, bodily-kinetics interpersonal and intrapersonal intelligence to solve problems and create products (Gardener and Hatch 1989).

The theory of multiple-intelligence has added further impetus to our understanding of human intelligence. In contrast, most definitions of intelligence focus on problem solving that is crucial for success in education. It is claimed that in most cases these tests are empirically determined and the investigators search for items that will predict who will succeed in education. However, the ability for example to perform a play, execute painting, undertake an experiment and manage organisation are not catered for. The MI theory considers intelligence in terms of the development and the break down of individuals' cognitive capacities under various kinds of organic pathology, the existence of abilities in certain individuals such as people with learning disabilities, the presence of intelligence in different species, and the presence of intelligence in different cultures, and evolution of intellect over a period of time. Overall, the MI theory argues that intelligence exists in different forms and therefore over-reliance on standardised tests may be unhelpful in predicting intelligence and performance.

#### *Age at onset and social functioning*

On the other hand, the American Association of Learning Disabilities, now known as the American Association of Intellectual and Developmental Disabilities (AAIDD) (Lichten and Simon, 2007), defines learning disabilities as a disability characterised by significant limitations both in intellectual functioning and adaptive behaviours as expressed in conceptual, social and practical adaptive skills (American Association of Mental Retardation, 2002). This is said to manifest before the age of 18. This definition also puts emphasis on two elements; age at onset (before 18 years), which in some cases could

mean during 'childhood'; and adaptive behaviour or social functioning. Although this definition is seen as a shift away from the organic models and emphasises mutability and environmental interactions in the production of social competence and incompetence (Simpson, 2007), there are still controversies surrounding this definition.

Firstly, the inclusion of age 18 years is questioned. Some commentators such as Simpson argued whether the age at onset is relevant or necessary at all for the definition (Simpson, 2007). It is further claimed that the persistence of the developmental period in the definition is not justified in terms of completeness or accuracy (Simpson, 2007). A particularly common argument relates to brain injury, including epilepsy and meningitis which are common in adults. It is argued that there is a lack of proven medical reasons to justify that these cognitive impairments when present in children should be regarded as different from those occurring during adulthood (Simpson, 2007). However, the customary approach is therefore to include the organically disabled person, this includes the prenatal, perinatal as well as the postnatal causes of learning disabilities (Simpson, 2007; Zigler and Hodapp, 1991). Simpson argued that limiting the definition of learning disabilities to the developmental age was the unforeseen product of the development of medico-pedagogical practices and were aimed at children around which a discourse was built and subsequently reinforced by IQ testing (Simpson, 2007). Therefore it was presumed not only highly contingent, but far from inevitable (Simpson, 2007). Secondly, the element of social functioning although relevant to recent definitions is not entirely free from criticism and this continued to be debated. Its main criticism are claimed to originate from the assumption that labelling people with learning disabilities as having social incapacities may 'stigmatise' the individual (Mittler, 1979; O'Brien, 2001, 2003).

There are also other problems associated with the use of social incapacity and its social context. It is argued that social functioning

can vary depending on the task and context. Therefore an individual with a given level of learning disabilities might cope and function differently under different environments or situations (Landesman-Dwyer, 1991 in: Gardner and Hatch, 1989; O'Brien, 2001).

#### *Administrative definition*

Finally the third definition which is relevant to this study is the 'administrative' definition. This definition is based on contact with services. According to these authors, people who are in contact with learning disabilities service constitute the best-fit population of individuals with learning disabilities (Richardson et al., 1986). Although this definition is clearly independent of IQ, age and social functioning compared with the other definitions, it remains unpopular among other schools of thought. Critics of this definition, for example Mansell, holds the view that services differ from place to place and may require different entry criteria for example, special schools (Mansell, 1990). Even when they do have the same entry requirements, it is not automatic that every individual will gain access but it may be dependent on approval from their parents, services availability and other local requirements (O'Brien, 2001). In addition, health services are redesigned and change over time and new philosophies are constantly being developed, refined and evaluated according to changing policies and consumer needs. Therefore, the entry criteria for individuals are also bound to change accordingly (O'Brien, 2001). Therefore, individuals identified by this approach may not reflect the learning disabilities population overall (Beadle-Brown et al., 2006).

#### *Definition of learning disabilities in this study*

As discussed above, there is no 'gold standard' definition for learning disabilities. All definitions tend to be 'operational'. However, for the purposes of this study, another operational definition is adopted. The learning disabilities population will be defined as *individuals who are either receiving or eligible for learning disabilities services*. This is

because individuals may not be receiving learning disabilities services due to limited availability or the person may not want to be identified as a service user although eligible.

Nevertheless, this definition is bound to also have its own weaknesses because the criteria for determining eligibility can be subjective and may remain open to negotiation. For example these operational definitions are contextual and time-bound and also dependent on the administrator.

The above definitions reflect the changes which have occurred within the international system of classifications from the early 1980s (Dahl, 2002; Stucki et al., 2002) from an emphasis on a medical-biological view of disabilities to a bio-psycho-social approach (Dahl, 2002).

### *2.2.2 Social and medical models of disability*

It is argued that traditionally, disability has been perceived as a 'medical' condition of an individual. This is referred to, as the 'medical model' of disability. It is argued that this model tends to locate disability within the individual and suggests that given a particular regime or treatment to follow, the problem will be 'fixed', 'cured' or restore 'normal' bodily functioning (Law et al, 2007). It further suggests that there is a 'normal' state of mind or health which can be attained (Law et al., 2007; Oliver, 1996, 1998). This medical model usually refers to disease as an individual pathology (Chappell et al., 2001). This at times results in individuals being seen in terms of diagnostic categories with a focus on rehabilitating specific difficulties (Smart and Smart, 2006). Therefore, research regarding impairment and disabilities has been dominated by positivist theories (Oliver, 1998) with the emphasis on cure as a means of reducing the impairment. This is often by means of clinical interventions through methods such as controlled trials, randomised samples and structured questionnaires (Oliver, 1998) with limited application of qualitative academic discourse. However, it is argued that there has been a

paradigm shift and the positivists' philosophy has been challenged as failing to value people and to celebrate difference (Jordan and Bryan, 2001).

Alternatively, the 'social model' sees disability as socially constructed (Dewsbury et al., 2004; Goffman, 1963). This describes disability as arising from barriers created by society and not from the individual (Chappell et al., 2001; Dewsbury et al., 2004; Oliver, 1996). This model focuses on societal barriers and what can be done to remove those barriers rather than on the nature of specific impairments. Oliver posited that the social model does not deny the problem with disability but locates it squarely within society (Oliver, 1996). It is not individual limitations, of whatever kind, which are the causes of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully addressed in communities (Oliver, 1996). Therefore the focus for change is the societal environment rather than the individual, and the environment must be adapted to accommodate differences and be inclusive of all members of the community (Law et al., 2007).

The social model views disabled people as citizens with rights who are entitled to their views regarding issues that affect their lives and deserve to be treated with respect (Dewsbury et al., 2004). It redefines the perceptions of disabled people by reframing disabilities as an outcome of interactions. The ability to communicate and interact is a powerful tool in this regard. Therefore there is a need to reduce societal barriers that act as impediments and to create opportunities to enable people with learning disabilities to participate fully in society. Also, the social model encourages methodological commitment (Oliver, 1998). This includes the involvement of disabled people's views and experiences regarding the provision and delivery of health services.

Within the mid 1980s, Disabled People International made a clear distinction between impairment and disability: impairment is the functional limitation within the individual caused by physical, mental or sensory impairments. Since then numerous international classification systems have been in operation with the focus on incorporating social perspectives of disability.

The most recent WHO system known as the International Classification of Functioning, Disability and Health (ICF) consists of both the International Classification of Diseases and Related Health Problems (ICD10) and International Classification of Functioning and Health (ICF) as the main international classification of health, comprising both medical and social perspectives (The World Health Organisation, 2001). The ICF framework has two main parts: body functions and body structure, activity and participation constitute one part of the framework; and the other part is made up of contextual elements, environmental and personal factors. The overall approach in the framework is 'functioning' to indicate positive aspects or neutral wording of disabilities and the negative aspect is called disability (The World Health Organisation, 2001). The above conceptualisation clearly places the ICF in line with current understanding of 'disabilities' and 'functioning'. It regards disabilities not only as a consequence of a health condition, but also as determined by the physical environment, the services available in the society, values and social legislations which are seen as environmental factors (Dahl, 2002). However, critiques of this system argue that the title and wording 'International Classification of Function, Disabilities and Health' is confusing thus, forwarding the argument that the system creates the impression that an individual may have to classify functioning and disabilities separately and thereafter classify health (Dahl, 2002). Furthermore, it is argued that the distinction between disability and functioning is not explicit since there is no fixed limit to determine whether a person has learning disabilities or not (Dahl, 2002). Another popular commentator such as Pfeiffer argued that as long as one of the

conceptual bases of ICF remains a medical model (structure and function), disabilities issues will continue to be medicalized (Pfeiffer, 2000). Pfeiffer further argued that it is not surprising that the new system of classification (ICF) is still unpopular among other commentators, for example, disabilities rights movement groups (Pfeiffer, 2000).

These debates reflect the complexities regarding classifications and definitions of learning disabilities, and the search for a standard definition and classification system is still a challenge for practitioners and researchers. It is worth noting that the influence of the literature on the definition adopted in this study has been significant in particular, the services contact definition. It is argued that service provision for people with learning disabilities has always been a subject of philosophical debates in particular the medical and social model dichotomy (O'Hara et al, 2010). However, it is claimed that these two approaches are not mutually exclusive (Lopez-Rangel et al., 2008). Therefore, the emphasis is on philosophical and cultural enrichment and cross-fertilization of ideas and actions between medical and other health professionals (O'Hara et al, 2010).

As mentioned earlier, although a definition of learning disabilities for this study was decided upon, it has been used with some caution because it is contextual, time-bound and also subject to different interpretations.

### *2.2.3 Prevalence of learning disabilities*

Within the confines of this thesis it is not possible to engage in a lengthy discussion about the causes and prevalence of learning disabilities, instead, key and relevant issues will be presented.

It is argued that although figures exist for the number of people with learning disabilities within the UK population, it is difficult to obtain reliable figures (Whitaker, 2004). Studies on prevalence rates are

especially lacking regarding adults. By comparison, figures are more easily obtained relating to children when most of the population is at school and learning disabilities have been identified (Beange and Taplin, 1996; Janicki et al., 1999). Variations in prevalence rates also reflect the operational definitions of learning disabilities (Bowley and Kerr, 2000; Hou et al., 1998; Whitaker, 2004). Rates also have been found to vary among different regions and countries (Beange and Taplin, 1996). In the UK estimates are that the learning disabilities population is between 2.0-2.5% of the general population (Cooper et al., 2004, 2006; Whitaker, 2004). Given that demographics are said to be changing, the population of people with learning disabilities has risen to 1.2% per year over a 35 year period 1960-1995 (McGrother et al., 2001). Although follow up studies are lacking, a further rise of 11% was projected over a 10 year period 1998- 2008 (McGrother et al., 2001). In the case of mild to moderate learning disabilities prevalence rates are estimated to be between 2.5-3% (Emerson, 2001; Roeleveld et al., 1997) and apply to about three to four per 1000 of the population in England and Wales (Department of Health, 2001). By applying this calculation, it has been estimated that there are about 7-30 people with mild to moderate learning disability in each general practice across the UK (Emerson, 2001).

In other countries for example the Netherlands, the prevalence of people with learning disabilities is estimated as 0.7% (Wullink et al., 2007). In northern Sydney the overall prevalence has been quoted as 3.31 per thousand for people with severe learning disabilities, 2.19 per thousand and for individuals with mild learning disabilities (Beange and Taplin, 1996). These differences in prevalence rates may also relate to variations in definitions and criteria for identifying people with learning disabilities.

Similarly, the aetiologies of learning disabilities are also varied and dependent on the learning disabilities syndrome however, other causes remain unknown.



#### *2.2.4 Aetiology of learning disabilities*

Learning disabilities are seen to be caused by a range of pathological processes (Bowley and Kerr, 2000). Individuals with learning disabilities are generally categorised by the so-called 'two-groups' approach: (1). Those individuals whose learning disabilities has no apparent organic cause (familial or cultural-familial disabled persons) (Zigler and Hodapp, 1991). These learning disabilities may be due to polygenic factors for example, receiving fewer genes for intelligence from their parents, growing up in a poor environment and a combination of polygenic and environmental factors or environmental factors acting early in the developmental stages (Rosa et al., 2001; Simonoff et al., 1996; Zigler and Hodapp, 1991). It is claimed that individuals with these types of learning disabilities generally have IQ which ranges from 50-70 and are differentiated from non-disabled individuals by demonstrating fewer biological and or behavioural characteristics (Zigler and Hodapp, 1991). (2). The organically impaired persons (whose learning disabilities have clear organic causes whether of prenatal, perinatal or postnatal origin) and other conditions affecting the developing foetus. Prenatal factors include; the genetic syndromes for example Down syndrome, Fragile-X, rubella, thalidomide. Perinatal factors include anoxia, prematurity, and other birth-related events, while the postnatal causes include the after-effects of meningitis, head trauma or brain injury or other insults to the brain (Zigler and Hodapp, 1991). Although it is difficult to obtain exact figures, estimates are that from one half to three quarter of all learning disabilities are of the familial type and the remaining one quarter to one half are affected by organic causes (Zigler and Hodapp, 1991).

However, there has been increased research over the last decade regarding the aetiology of learning disabilities. In particular, genetic advances have been made into the individual causes of learning disabilities (Bowley and Kerr, 2000; Mazzocco, 2000). It is argued that some inheritable disorders approach 100% penetrance but in this

case even clinical presentation may be affected by environmental factors (Hornig and Lipkin, 2001). Dietary elements have also been reported to be associated with the development of intelligence (Gillberg and Soderstrom, 2003). For example, possible links between breast feeding and the development of intelligence has been forwarded (Morley, 2002). Although an increasing number of single gene conditions and subtle chromosomal changes that lead to mild to moderate outcome are known, other causes are still unknown (Muir, 2000; Raymond and Tarpey, 2006). Whilst some causes may be easily identified for example genetic disease or sequelae of central nervous system infection or head injury often in the case of severe learning disabilities, others remained undiscovered especially in relation to mild learning disabilities (Hou et al., 1998).

In summary, as seen above the causes of learning disabilities are many and varied. It is argued that the commonest causes of learning disabilities remain unknown and that the greater proportion of the causes are polygenic (O'Hara et al., 2010).

A review by O'Hara and colleagues classified the known congenital causes into various groups. These include:

- i). Single gene and chromosomal syndrome e.g. Down syndrome, Fragile-X, Prader-Willi syndrome, Angelman syndrome
- ii). Inborn errors of metabolism e.g. Phenylketonuria, Gaucher disease, galactossaemia, Cretinism
- iii). Fetal infection e.g. cytomegalovirus, congenital syphilis, congenital rubella syndrome
- iv). Fetal alcohol syndrome e.g. microcephaly, cerebellar hypoplasia
- v). Congenital CNS structural anomalies e.g. open neural tube defects
- vi) Environmental causes e.g. injury and trauma (O'Hara et al., 2010). However, for the purpose of this thesis, only those conditions and syndromes known to be associated with epilepsy will be discussed.

## 2.3 Learning disability syndromes associated with epilepsy

### *2.3.1 Down syndrome*

It is argued that Down syndrome is the commonest chromosomal cause of developmental delays (Barnhart and Connolly, 2007). Down syndrome is caused by a trisomy or translocation on the 21<sup>st</sup> chromosome (Chapman and Hesketh, 2000; Zigler and Hodapp, 1991). It is claimed that trisomy 21 is present in about 93-95% of individuals with Down's syndrome (Finesilver, 2002) whilst the remaining causes are due to translocation when parts of chromosome 21 break off and attach to another chromosome and also mosaicism (Finesilver, 2002; O'Hara et al., 2010). The increase in protein expression of genes on chromosome 21 triggers the development of foetal brain structure and subsequent behavioural effects across the life span of the individual with Down syndrome (Chapman and Hesketh, 2000; Lennox and Eastgate, 2004). A small area of the distal part of the long arm of chromosome 21 is said to be associated with many of the physical characteristics of Down syndrome particularly, facial features, congenital heart diseases, duodenal stenosis and some components of learning disabilities (Chapman and Hesketh, 2000). Other features include impaired auditory and short term memory, limited verbal fluency and expressive language delay (O'Hara et al., 2010)

In England and Wales prevalence is said to be between one and two per 1000 births, with the total prevalence showing an upward trend due largely to increasing maternal age (Bell et al., 2003). Down syndrome accounts for up to third of all people with severe to profound learning disabilities and for a much smaller, albeit significant fraction of moderate to mild learning disabilities (Gillberg and Soderstrom, 2003). It is more likely to be present in children born of older parents (Zigler and Hodapp, 1991). A significant number of

people with Down syndrome develop Alzheimer's disease as they grow older, usually in their mid forties (Gillberg and Soderstrom, 2003;Lott and Head, 2001;Roizen and Patterson, 2003). This is estimated to set in 20 years earlier than in the general population (Lennox and Eastgate, 2004).

In addition, Down syndrome is associated with high risks of epilepsy and seizures which are usually the clonic/tonic type (Lennox and Eastgate, 2004). Epilepsy is a significant cause of secondary disability and has been recognised as an important cause of morbidity in Down syndrome (McVicker et al., 1994). A community-based study by McVicker and colleagues in a population of 191 adults with Down syndrome reported a prevalence rate of 9.4%. This prevalence rate was reported to increase with age to about 46% in those over the age of 50 years (McVicker et al., 1994). However, as mentioned earlier, the diagnosis and classification can be more difficult in the learning disabilities population due to limited cognitive and communication skills (McVicker et al., 1994).

### *2.3.2 Fragile-X*

Fragile-X is caused by genetic mutation on the X-chromosome which includes a trinucleotide repeat sequence (Gillberg and Soderstrom, 2003;Mazzocco, 2000). The mutation is characterised by hyper-expansion of the repeat sequence leading to down-regulation of the gene (Murray et al., 1997). It is considered the most commonly known hereditary cause of learning disabilities affecting both males and females in an X-linked manner (Mazzocco, 2000). It affects about 1:3000 children (Gillberg and Soderstrom, 2003). Young males are differentiated from adults with learning disabilities by showing more impairments in motor skills, increased initial avoidance, attention deficits and hyperactivity (Kau et al., 2000). Autistic features are common in people with Fragile-X syndrome and are also linked with expressive language delay (Gillberg and Soderstrom, 2003). It has been claimed that overall, females with Fragile-X syndrome have less

challenges and difficulties compared with males (Turk, 1992). Other features include restricted interests and poor social interaction (O'Hara et al., 2010).

There is a common association between Fragile-X and epilepsy, usually involving clonic/tonic and complex partial seizures (Lennox and Eastgate, 2004). Epilepsy is said to occur in about 10-20% of individuals with fragile-X syndrome (Berry-Kravis, 2002). It is claimed that about 20% of children with fragile-X have seizures which are often well controlled (Berry-Kravis, 2002; O'Hara et al., 2010). A US cohort of 136 people with fragile-X revealed that seizures occur in 13.3% of males and in 4.3% of females (Berry-Kravis, 2002). However, EEG findings were available for only 35 individuals (Berry-Kravis, 2002). Therefore, the role of available witness accounts in particular from carers is crucially important.

### *2.3.3 Angelman's syndrome*

Angelman's syndrome is caused by the loss of the maternal contribution to the same proximal portion of chromosome 15. It most commonly results from de novo interstitial deletion in the 15q11-q13 region. In a few cases, it is caused by paternal uniparental disomy or an imprinting mutation (Moncla et al., 1999). It is associated with obsession and compulsive behaviours, limited speech, hyperactivity, insomnia and eating disorders (Gillberg and Soderstrom, 2003; Moncla et al., 1999). Other manifestations include epilepsy, severe developmental delay and microcephaly (Lennox and Eastgate, 2004; Moncla et al., 1999). Epilepsy and seizures occur in about 80% of individuals with Angelman's syndrome (Clayton-Smith and Laan, 2003). In childhood, different types of seizures are reported, ranging from tonic-clonic, atypical absence seizures, complex partial, myoclonic, atonic and tonic to status epilepticus (Clayton-Smith and Laan, 2003). It is argued that seizures occurring in Angelman's syndrome individuals are difficult to control with antiepileptic

medications in particular, among children (Clayton-Smith and Laan, 2003).

#### *2.3.4 Cerebral palsy (CP)*

Cerebral palsy refers to a group of permanent disorders affecting the development of movement and posture leading to limited activities. These disorders are attributed to non-progressive disturbance that occurred in the developing fetal or infant brain (Rosenbaum et al., 2007). Cerebral palsy is caused by many factors. Multiple births, maternal infection and foetal thrombophilic conditions all predispose to the development of CP in infants (Petersen and Palmer, 2001). It is claimed that about 90% of CP is caused by antenatal issues and 10% by anoxia at birth (Lennox and Eastgate, 2004). Cerebral palsy affects 1:500 children in the UK and is commonly associated with epilepsy. Evidence suggests that hearing impairments are reported both in people with learning disabilities and cerebral palsy (O'Hara et al., 2010). It is claimed that hearing deficits are about 40 times more common among people with learning disabilities than the general population (Gillberg and Soderstrom, 2003). Also, it is argued that the motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, epilepsy and musculoskeletal problems (Rosenbaum et al., 2007). Therefore, communication may further be compromised in individuals whose cerebral palsy co-exists with learning disabilities. It is estimated that about 30% of people with a combination of CP and learning disabilities have epilepsy (Gillberg and Soderstrom, 2003). In a recent study among a population of 374 children with CP in Norway, learning disabilities was present in 31%, 28% cases of epilepsy were found, 28% had severely impaired speech and 5% had impaired vision (Andersen et al., 2008). It is claimed that multiple seizure types and many epileptic syndromes are present in individuals with cerebral palsy (Rosenbaum et al., 2007). Another retrospective study, in a Swedish cohort of 146 people with cerebral palsy, found 38% of them had epilepsy (Carlsson et al., 2003).

### *2.3.5 Tuberous sclerosis (TS)*

Tuberous sclerosis complex is an autosomal dominant disorder caused by mutations in the TSC1 and TSC2 genes on chromosomes 9 and 16 respectively (Devlin et al., 2006). A prevalence rate was reported by (Joinson et al., 2003) as 1:10,000, but it is estimated by (Holmes and Stafstrom, 2007) to be 1:6,000. Diagnosis is based on clinical symptoms. However, it is argued that this can be difficult to diagnose due to variable phenotypic expressions (Holmes and Stafstrom, 2007). Estimates are that 80% of affected people have a new mutation and the remaining 20% are said to have an inherited TSC gene from a parent (Holmes and Stafstrom, 2007). The mutations result in the formation of tumours which can develop in all parts of the body but are commonly found in the skin, eyes, heart, kidneys, lungs and brain. The tumours are the basis for the development of various complications such as cardiac/renal dysfunction, epilepsy, learning disabilities, autism and hyperactivity (Holmes and Stafstrom, 2007; Joinson et al., 2003). Epilepsy occurs in about 80-90% of affected individuals with TS who are often difficult to treat with a reported poor responses to antiepileptic medications (Holmes and Stafstrom, 2007; Wilcox and Kerr, 2006). Depression and anxiety disorders are said to be common among individuals with TS and epilepsy (Asato and Harden, 2004).

### *2.3.6 Rett's syndrome*

This is caused by a disorder of unknown aetiology and has been known to occur almost exclusively in females (Gillberg and Soderstrom, 2003) but has been found in males with Klinefelter's syndrome (Schwartzman et al., 2001). It is characterised by apparent normal development in the first year of life and followed by the loss of acquired hand skills and speech together with retarded growth hyperventilation and learning disabilities. All individuals with this syndrome have profound to severe, but occasionally moderate, learning disabilities with limited speech (Gillberg and Soderstrom, 2003). Other characteristics include, vasomotor instability and

refractory errors (Lennox and Eastgate, 2004). Rett's syndrome is also known to be associated with epilepsy (Lennox and Eastgate, 2004; Schwartzman et al., 2001). Estimates are that about 60-70% of people with Rett's syndrome will develop epilepsy (Moser et al., 2007). However, as evidence suggests that the severity for epilepsy reduces after 20 years, this requires careful monitoring to inform the withdrawal of antiepileptic medications to minimise adverse effects (Moser et al., 2007).

### *2.3.7 Phenylketonuria (PKU)*

This is a hereditary and a metabolic disease characterised by phenylalanine hydroxylase (an enzyme required for the conversion of phenylalanine into tyrosin) (Poustie and Rutherford, 2006). Untreated PKU may lead to learning disabilities, sometimes of a profound nature and also hypopigmentation. Phenylalanine is said to be toxic to foetal development and severe disorders occur in the children of women whose PKU is untreated during pregnancy (Feillet and Agostoni, 2010). It is claimed that dietary advice regarding the amino acid phenylalanine during neonatal period prevents the development of learning disabilities (Feillet and Agostoni, 2010; Poustie and Rutherford, 2006). This enables the affected individuals to live almost normal lives (Feillet and Agostoni, 2010). However, the symptoms of untreated PKU which manifest in the brain are diverse and range from mild cognitive impairments to severe learning disabilities with motor impairments e.g. hyperactivity, extra-pyramidal syndromes, impaired social abilities, challenging behaviour, self-harm and epilepsy (Lennox and Eastgate, 2004; Martynyuk et al., 2007).

## **2.4 Learning disabilities and co-existing health conditions**

People with learning disabilities are known to have a wide range of associated health problems (Bowley and Kerr, 2000). It is estimated that up to a quarter of all people with epilepsy have learning disabilities, and up to a third of all individuals with learning disabilities



have epilepsy (Lhatoo and Sander, 2001). In addition, it is estimated that people with learning disabilities on average have 5.2 medical conditions per person (Lennox and Eastgate, 2004) and that about half of these are either unrecognised or are poorly managed (Beange and Taplin, 1996; Lennox and Eastgate, 2004). Commonly reported conditions include: hypertension; obesity; heart disease; cancer; gastrointestinal disorders; abdominal pain; respiratory disease; chronic UTI; oral disease; musculoskeletal conditions; osteoporosis, thyroid disease, visual and hearing impairments (Nocon and Leese, 2004). The prevalence of these conditions appears to be linked to age and also the severity of the learning disabilities (Sutherland et al., 2002). It is argued that certain learning disabilities syndromes may also be associated with increased risk of specific health conditions (Sutherland et al., 2002). For example, individuals with Down syndromes are known to be associated with early onset of geriatric health conditions (Councilman, 1999 in: Sutherland et al., 2002) and cardiac abnormalities (Patja et al., 2001). Moreover, it is estimated that 30% of all people with a combination of cerebral palsy and learning disabilities have epilepsy (Gillberg and Soderstrom, 2003). Although it has been reported that adults with learning disabilities tend to experience similar morbidities to the general population (van Schrojenstein Lantman-De Valk et al., 2000), epidemiological evidence suggests that people with learning disabilities are more susceptible to psychiatric and physical illness compared with the general population (Prasher and Kapadia, 2006; van Schrojenstein Lantman-De Valk et al., 2000). The reasons for these are said to include both biological and psychological risk factors (Prasher and Kapadia, 2006).

Epilepsy is a common co-existing health condition in individuals with learning disabilities (Pary, 1993). Anxiety disorders are known to be associated with impaired quality of life and are further complicated by the occurrence of seizures (Vazquez and Devinsky, 2003; Vazquez et al., 2007). Furthermore, it is claimed that epilepsy is psychologically

stressful and leads to a wide range of pathophysiological changes that can trigger various physical and psychiatric illness and hence contributes to increase in mortality and co-morbidity rates (Yuen et al., 2007). Other findings also suggest high rates of psychiatric illness among individuals with learning disabilities. For example, the prevalence rates of psychiatric illness in children with learning disabilities are estimated to be 40% (Emerson, 2003) and are known to be higher among adults with learning disabilities (Cooper, 1997). This reflects previous study findings which indicate that prevalence rates of psychiatric and behavioural problems among people with learning disabilities ranged between 10% and 80% compared with the general population (Borthwick-Duffy, 1994).

It is argued that the most frequently reported morbidity is maladaptive behaviour (Bowley and Kerr, 2000). A wide range of terms are used to encompass maladaptive behaviours, including: problem behaviours, challenging behaviours, aberrant behaviour and behaviour disturbance (Smith et al., 1996) and also emotional or conduct behaviours (Tustin et al., 1999). However, the definition of maladaptive behaviour continues to be debated (Smith et al., 1996). In some studies, it remains unclear whether the classification of behavioural problems includes or excludes individuals with psychiatric illness, or whether they are considered as a dual diagnosis (Smith et al., 1996). Prevalence rates of problem behaviours vary largely as a result of the variations in the definitions, study design and case ascertainment (Smith et al., 1996). Problem behaviours are known to be common characteristics of dementia which commonly occur among people with learning disabilities in particular, those with Down syndrome (Cooper, 1997).

It is claimed that challenging behaviour is probably the single most researched maladaptive behaviour in the field of learning disabilities (Hastings, 1997). Health and social care professionals have defined challenging behaviours as 'actions that are difficult to manage'

(Hastings, 1997). Emerson and Bromley define challenging behaviour as 'culturally abnormal behaviours of such a severity, frequency and duration that the physical safety of the individual and the general public is likely to be put at risk, or behaviour which is likely to seriously limit the individual chances to access services (Emerson and Bromley, 1995). Problem behaviours include: self-injury behaviour; aggression and destruction of properties; sexually inappropriate acts and 'stereotyped' behaviour (Bailey et al., 2006;Hastings, 1997).

A number of studies investigating care staff attributions and responses to the challenging behaviours displayed by people with learning disabilities indicate that the individuals may present challenging behaviours for various reasons, for example, as social reinforcement; for communication and expression of needs. Also, as a result of the nature of the physical environment as well as the emotional state of the individual (Bailey et al., 2006). It could also be assumed that maladaptive behaviours or challenging behaviours are forms of communication but little or no research has investigated the individuals' views of communication among people with learning disabilities.

Furthermore, within a learning disabilities population, it was observed that people with an apparently good level of understanding but no speech have significantly more behaviour problems than those with good speech (Bott et al., 1997). This is a demonstration that communication may be a function of challenging behaviours. However, the tendency for services to focus exclusively on expressive communication behaviours of people with learning disabilities has been widely reported (Kevan, 2003). This highlights the need for services to pay closer attention to the receptive communication skills to identify the individuals communication needs (Kevan, 2003).

### *2.4.1 Mortality*

People with learning disabilities experience health inequalities compared with the general population (Cooper et al., 2004). Although life expectancy for people with learning disabilities is said to be increasing in particular, for people with mild intellectual disabilities, they continue to experience higher health inequalities compared with the general population (Cooper et al., 2004; Patja et al., 2000). Furthermore, research findings indicate that although longevity among adults with learning disabilities has increased over the past 30 years, they still tend to have shorter life expectancy in comparison with the general population (Janicki et al., 1999; Patja et al., 2000).

It is claimed that people with learning disabilities have higher levels of health needs than the general population but these are often unrecognised and unmet leading to premature death (Cooper et al., 2004; Lennox and Eastgate, 2004). Limited or lack of communication may serve as a significant barrier to accessing primary health care and may be a marker of the unrecognised health needs of people with learning disabilities (Cooper et al., 2004) leading to increased mortalities. In most studies, mortality figures are confounded by variables such as age (Perakis et al., 1995), gender (Durvasula et al., 2002; Merrick, 2002) and the severity of the learning disabilities (Durvasula et al., 2002; Lavin et al., 2006; Merrick, 2002) as well as the presence of co-existing health conditions (Forsgren et al., 1996, 2005b; Patja et al., 2001). It is claimed that mortality rates from all causes of death are about threefold for people with learning disabilities compared with the general population (Decouflé and Autry, 2002; Durvasula et al., 2002; Forsgren et al., 1996, 2005a, 2005b; Tyrer et al., 2007). In a UK population-based study to investigate the extent of excess mortality among people with learning disabilities compared with the general population between 1993-2005, the overall mortality was found to be more than three times higher among the learning disabilities population (Tyrer et al., 2007). This was also found to vary significantly with age. Significant differences

were also observed in the younger age group where the standard mortality rates (SMR) were about nine times higher in men between the ages of 20-29 (SMR=883) and about 17 times higher in women in their 20s (SMR=1722). This trend was observed to diminish with increasing age (Tyrer et al., 2007). Moreover, in a five year database study between 1996-2001 in Ireland revealed the average age at death as 45.68 years with no differences in life span between men and women (Lavin et al., 2006). It was noted further that individuals living at home have the shortest lifespan while those in hospitals and residential environment the longest. This may be a reflection of the levels of support and services provided in these settings (Lavin et al., 2006). A similar population based study in Northern Sydney reported the standard mortality rate (SMR) for men and women as 4.1 and 6.2 respectively (Durvasula et al., 2002). The severity of the learning disabilities appears to be a strong predictor of mortality in most studies (Durvasula et al., 2002;Lavin et al., 2006;Merrick, 2002;Patja et al., 2001). The probability of survival decreases as the severity of the learning disabilities increases (Bowley and Kerr, 2000). However, it was observed that among people with moderate to profound learning disabilities there were no discernible differences in death rate (Tyrer et al., 2007).

As mentioned earlier, the presence of additional health conditions is a predictor of increased mortality. However, of all causes of death, pneumonia has been reported as the single specific cause of death in about 83% of cases (Patja et al., 2001). The co-existence of epilepsy is also reported as a marker of mortality in people with learning disabilities (Cockerell, 1996). Epilepsy is known to be the most common neurological cause of death among people with learning disabilities, often occurring among the younger age groups (Patja et al., 2000, 2001). The mortality rates in people with learning disabilities and co-existing epilepsy is said to be five times higher compared with the learning disabilities population overall (Forsgren et al., 1996, 2005a, 2005b).

Other research findings suggest that the aetiology may play a part in life expectancy among adults with learning disabilities (Sutherland et al., 2002). Syndrome-specific learning disabilities are known to influence mortality to a larger extent compared with the general learning disabilities population. Down syndrome has been commonly reported to be associated with increased mortality among people with learning disabilities compared with other unknown causes (Patja et al., 2000, 2001; Tyrer et al., 2007). In another study, Prader-Willi syndrome has also been found to be associated with higher rates of mortality compared with individuals with other learning disabilities syndromes (Einfeld et al., 2006).

#### *2.4.2 Mortalities in community and institutional settings*

Differences in mortality rates in community and institutional populations have been reported (Sutherland et al., 2002). Some researchers reported higher mortality rates in institutional populations (Janicki et al., 1999). These authors claimed that the low mortality rates among a community-based population may relate to the increased numbers of adults with learning disabilities who are residing in communities following the closure of long-stay institutions. As a result the majority of them may not be in touch with social services thus, death statistics may not be available (Janicki et al., 1999). However, other researchers reported to the contrary and considered mortality as a function of residential placement (Sutherland et al., 2002) with significantly higher mortality rates among community dwellers than individuals in residential settings (O'Brien and Zaharia, 1998; Shavelle and Strauss, 1999). Nevertheless, it is argued that comparing mortalities in 'community' and 'institutional' individuals is irrelevant because differences in environment may not necessarily be an indicator of mortality (Sutherland et al., 2002).

Furthermore, although different environments may not be direct causes of death, certain settings may influence mortality risk. For

example, life-style choices in these environments may be different which may have implications for epilepsy prognosis. Also, individuals in the community may require additional support from carers and health care professionals to manage their conditions and therefore, the needs for effective communication is essential (Kerr et al., 1996).

## 2.5 Epidemiology of epilepsy

Despite the fact that epilepsy is among the most serious neurological conditions, thorough understanding of its epidemiology remains lacking (Bell and Sander, 2001, 2002; Sander, 2003a; Sander and Shorvon, 1996). These differences are partly due to methodological problems as well as failure by some researchers to recognise the 'heterogeneous' nature of epilepsy (Bell and Sander, 2001, 2002; Sander, 2003a; Sander and Shorvon, 1996).

### *2.5.1 Definitions of epilepsy*

As in the case with learning disabilities, there are several definitions for epilepsy. However, unlike learning disabilities, these definitions are mostly medically based. It is estimated that there are about 16 operational and 18 conceptual definitions for epilepsy, approved by the International League Against Epilepsy (ILAE) (Engel, 2006b). With the increasing knowledge and research in the field of epilepsy, it was considered necessary that a standard definition for epilepsy and epileptic seizure is found to facilitate communication among medical and non-medical professionals. The ILAE has reached a consensus definition for epileptic seizures and epilepsy. An epileptic seizure is defined as a transient occurrence of signs and/or symptoms due to abnormally excessive or synchronous neuronal activity in the brain (Fisher et al., 2005). Epilepsy refers to a disorder in the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiologic, cognitive, psychological and social consequences of this condition. The definition of epilepsy requires the occurrence of at least one epileptic seizure (Fisher et al., 2005). This

is viewed as a helpful and operational definition applicable both in medical and non-medical settings (Fisher et al., 2005).

### *2.5.2 Classification of epilepsy*

The classification systems for epilepsy and seizures have undergone significant changes and revisions since the early 1970s. Recently there has been growing interest in the field of epilepsy regarding a standard classification system. However, it is argued that despite these revisions, the classification systems remain too complicated to be of general use in clinical practice and epidemiological research and fail to reflect recent advances in neuroimaging and neurogenetics (Everitt and Sander, 1999). Whilst some commentators claim that the current classification systems (1989) are not holistic enough for the classification of adults (Everitt and Sander, 1999; Kellinghaus et al., 2004) but are generally agreed to be more useful within the child population (Engel, 2006a, 2006b), others argue that there is no need for a systematic classification of epilepsies; however, there is a need to concentrate on reaching consensus based on current available knowledge of epilepsies. It is argued that 'if we cannot be botanists let us accept ourselves as gardeners and cultivate the plants we have learnt to identify and grow even if we are unsure or do not know which thallophyte family they belong to' (Avanzini, 2003 in: Fisher, 2003). Currently, classifications of epilepsies are based on seizure types and epilepsy syndromes or epilepsies (Bell and Sander, 2002; Bell et al., 2003).

### *2.5.3 Seizure types*

The classification of seizures is mostly done according to the ILAE system which is based on clinical and electroencephalographic (EEG) features of the seizure (Bell and Sander, 2001). The international league against epilepsy (ILAE) classified seizures into three main groups. These are: (1) generalized; (2) partial (localization-related) and (3) unclassified. Generalized seizures are seizures which affect both cerebral hemispheres from the onset of the seizure; while in



partial seizures the epileptic activity is limited to a focal area of the brain (Bell and Sander, 2001).

Generalized seizures are further divided into: tonic-clonic; absence; myoclonic; atonic (sudden loss of muscle tone); tonic (stiffening); and clonic (jerking) seizures. Partial seizures are also divided into simple partial seizures (where consciousness is preserved) and complex partial seizures (with the impairment of consciousness). Partial seizures may also become secondarily generalized when the epileptic activity spreads to involve both cerebral hemispheres (Bell and Sander, 2001). Although this classification scheme is universally accepted to have a proven clinical value in particular, by minimizing some of the ambiguities inherent with the 1981 classification system it remains unpopular among some authorities. It is argued that the 1981 classification system which is based on epilepsy seizures, operated at a time when knowledge in the field of epilepsy was relatively sparse. A particular criticism was that the classification relied heavily on phenomenology (Engel, 1998). Furthermore, it is argued that the ILAE classification of epileptic seizures (ICES) fails to reflect sufficiently, current knowledge and understanding of epilepsy and epilepsy syndromes (Engel, 1998). Therefore, it has limited application in the field of clinical pharmacology and epidemiological studies (Engel, 1998). Another argument forwarded is that this system of classification has failed to take into account, presumed pathophysiology and 'anatomical substrate' (Engel, 1998). A notable weakness of this classification system as argued, centres on its emphasis on impairment of consciousness to differentiate 'complex partial' from 'simple partial' seizures (Engel, 2001). It is claimed that impairment of consciousness is too strict and difficult to document but will require some conceptual changes (Engel, 1998). Furthermore, the 1981 system of classification has also been challenged for not being 'purely semiologic' and that often, 'post hoc' information and EEG data are required to use it properly, and the dichotomy of "partial" versus

“generalized” requires the need to avoid anatomic complication (Engel, 2001).

The revised version known as the international classification of epilepsies and epileptic syndromes (ICEES, 1989) defines an epilepsy syndrome as a disorder characterised by a cluster of signs and symptoms (Seino, 2006). It divides epilepsies into seizure types, for example localization-related, generalized or undetermined and further divides epilepsies into idiopathic, symptomatic or cryptogenic according to the putative cause (Bell and Sander, 2001). This classification system takes into account seizure type, EEG, prognostic as well as pathophysiological and aetiological data (ILAE, 1989). The 1989 ‘syndromic’ classification system has indeed addressed some of the anomalies and ambiguities inherent with the ILAE, 1981 version. For example, the 1989 classification system replaced the term “partial” with “localization related” (Engel, 2001). Although this classification system is considered useful for teaching and communication between physicians, it has not been entirely free from criticism. Critics argue that the system remains confusing, in particular, when applied in presurgical evaluation, and often misapplied in clinical pharmacological trials and epidemiological studies (Engel, 2001). It is claimed that there are still controversies regarding its application in adults, particularly focal seizures which occur mostly among adults (Engel, 2006a, 2006b). Also, although this ‘syndromic’ classification is useful for the diagnosis, prognosis, orientation of treatment and selection of appropriate investigation, its specificity is said to be variable and usually does not give information on the causes of epilepsy (Aicardi, 1994; Bauer, 1994). While some syndromes can be determined with precision, others are not and often the syndromes are found to be overlapping (Aicardi, 1994; Farrell, 1993). Application of the current ILAE classification systems to people in various settings have revealed that only 5-30% could be specifically identified according to the listed epilepsy syndromes (Osservatorio, 1996 in: Kellinghaus et al., 2004).

A task force set up by the ILAE to re-evaluate and revise the ICES and ICEES made a number of changes to the current classification system. For example, it was suggested that the term 'partial and localization related' be replaced with 'focal'. Also, it was recommended that febrile convulsion should be replaced by febrile seizures and suggested the omission of the term 'convulsion' (Engel, 2001). In addition, confusion regarding how the terms 'idiopathic' and 'cryptogenic' are defined was highlighted. It was argued that the term 'idiopathic' has been incorrectly used to refer to cases of unknown aetiology and pathogenesis (Wolf, 2006) but was in fact, a disorder 'unto' itself 'sui generis' (Engel, 2001). The issue with cryptogenic is said to be related to imprecision in the definition (Engel, 2001). Usually, it refers to conditions which are not idiopathic, or presumed to be symptomatic, when the aetiology has not been determined, but in other cases it refers to conditions in which the aetiology is not known whether they are idiopathic or symptomatic (Engel, 2001). Therefore, it is suggested that the terms idiopathic and symptomatic be retained but cryptogenic be replaced by a more appropriate term, such as symptomatic (Engel, 2001). Following this, the ILAE task force recognised that it would not be possible to replace the 1989 classification system with a new version which accommodates all clinical and research needs; rather, a diagnostic scheme made up of standardized terminologies and concepts to describe individual patients was proposed (Engel, 2001) and was approved (Engel, 2006a, 2006b).

A glossary of terms were also published for the descriptions of 'ictal' phenomena (Blume, 2001). However, a report by the ILAE core group indicated that none of its work has so far negated the current (1981, 1989) classification systems (Engel, 2006b). In fact, it is argued that the diagnostic scheme has actually created temporary confusion because of a mistaken assumption that it is a new classification system when it only represents a diagnostic schema (Engel, 2003).

Moreover, after years of extensive debates and consultation, a new classification system was introduced early this year (Berg et al., 2010). Although this current system is generally agreed to be congruent with recent technological advances in epilepsy for example the reintroduction of infantile spasms as seizure types and the changes from partial seizures to focal seizures, there are emerging weakness in particular, regarding changes in the classification of aetiologies. However, these are beyond the scope of this study.

#### *2.5.4 Aetiology of epilepsy*

The aetiology of epilepsy is said to be associated with many factors (Wilcox and Kerr, 2006). It is argued that in many cases it is difficult to ascertain the exact causes of the disease (Bell and Sander, 2001; Wilcox and Kerr, 2006). It has been estimated that about 60% of epilepsies have no clear causes (Bell and Sander, 2001) even with the aid of Magnetic Resonance Imaging (Bell and Sander, 2001).

In most epidemiological studies, the aetiology of epilepsy is defined as *idiopathic/cryptogenic* or *remote symptomatic*. *Idiopathic/cryptogenic*, indicating that the cause is unknown or in more recent classification, a known or presumed genetic aetiology while *remote symptomatic* indicate that a known precipitant of seizures prior to the first unprovoked seizure, was present (Brown et al., 1998; Buchhalter, 2004). *Idiopathic/cryptogenic* epilepsy is known to predominate from early childhood until about 40 years of age after which the frequency is similar to *remote symptomatic* epilepsy (Buchhalter, 2004) with the incidence of *remote symptomatic* seizures higher during childhood and at old age (Buchhalter, 2004).

#### *2.5.5 Risk factors for epilepsy*

The risk factors for epilepsy are known to vary with aetiology, age, and with geographical location (Bell and Sander, 2001; Sander and Shorvon, 1996). The risk of epilepsy in children, adolescence and

early adulthood are mostly associated with (a) congenital, developmental and genetic conditions (Sander, 2003b; Sander and Shorvon, 1996). These include malformation of cortical development and fixed motor deficits (cerebral palsy) (Buchhalter, 2004). The risk of epilepsy is said to rise from 7% of people with mild learning disabilities to about 67% in those with severe learning disabilities (Whitten and Griffiths, 2007). (b) Head trauma, central nervous system infections, and tumour which occurs at any age may lead to the development of epilepsy, although tumours are more likely to occur over the age of 40 years (Sander, 2003a; Sander and Perucca, 2003; Sander and Shorvon, 1996). It is estimated that at the age of 60 years and above, cerebrovascular diseases are the most common risk factors for the development of epilepsy (Sander, 2003b; Sander and Perucca, 2003; Sander and Shorvon, 1996). In addition, it is estimated that up to two-thirds of individuals will experience seizures over the age of 65 years (Buchhalter, 2004). Endemic infections such as malaria, neurocysticercosis and paragonomiasis especially in resource-poor regions are associated with epilepsy (Molyneux, 2000; Rwiza et al., 1992).

### *2.5.6 Diagnosis of epilepsy*

Accurate diagnosis is central to the successful management of epilepsy. However, it is often difficult to diagnose or rule out epilepsy with certainty. It is argued that both false positives and false negatives are common (Sander, 2003b; Sander and Shorvon, 1996). It is estimated that 20-25% of patients referred to specialists epilepsy clinics have a misdiagnosis of epilepsy (Kerr, 2001). For example, in England and Wales estimates are that up to a total of 92,000 people were misdiagnosed with epilepsy in 2002 (Juarez-Garcia et al., 2006). Also, it is claimed that the diagnosis of epilepsy can be extremely difficult in individuals with learning disabilities (Whitten and Griffiths, 2007). It is argued that in comparison with other neurological conditions, the vast majority of people with epilepsy do not show permanent physical signs and can only be diagnosed by taking a

history or by chance observation of a seizure (Sander, 2003b; Sander and Shorvon, 1996). Epilepsy diagnosis is also said to be based on a discretionary judgement, dependent on the experience of the diagnostician, and on the availability of a good quality witness account (Sander, 2003a). However, it is claimed that the descriptions of seizures by a witness are often incomplete or inaccurate (Rugg-Gunn et al., 2001; Sander, 2003a). This may be due to lack of knowledge and information regarding epilepsy. The description of epilepsy may also be misleading to the extent that non-epileptic attacks (for example, non-epileptic seizures, panic attacks, hallucination and movement disorders) may be misdiagnosed as epilepsy (Alvarez et al., 1998; Kerr, 2001; Rugg-Gunn et al., 2001). In particular, there may be difficulties in diagnosis among people with learning disabilities due to communication difficulties (Kerr, 2001; Kerr and Bowley, 2001b; Whitten and Griffiths, 2007) and more importantly individuals may not be aware of the events of epileptic activities. Therefore, the quality of witness accounts from carers is crucially important for the accurate diagnosis. Effective communication involving carers may contribute significantly to the diagnosis. Therefore, carers' basic knowledge regarding epilepsy is crucially important in this context. This will enable carers to communicate effectively with the service user and also to feedback epilepsy and seizure information appropriately to health care professionals.

### *2.5.7 Prevalence of epilepsy*

The prevalence rates of epilepsy are reported to vary. These variations may relate to diagnostic differences and cases ascertainment. Prevalence rates in developing countries are also reported well above those in developed countries. Studies conducted in the Scandinavian countries reported prevalence rates of around 5-6/1000 (Forsgren et al., 1996, 2005a).

In the UK the overall prevalence rate of epilepsy is estimated as 5.15/1000 (Brown et al., 1998). Further estimates are that more than

30,000 people develop epilepsy annually in the UK (Lhatoo et al., 2003). This is translated to an average of ten people with epilepsy in every general practice across the UK (Brown et al., 1993). In addition, another 15-25 patients are likely to have had a seizure in the past, but they may not have been treated or have stopped or failed to adhere to treatment (Brown et al., 1993). Other estimates are that up to 5% of the UK population will experience non-febrile seizures at some point in their life time (Bell and Sander, 2001; Brown et al., 1998). The prevalence of epilepsy excluding febrile convulsion, single seizures and inactive cases is usually estimated to be between 5 and 10 cases per 1000 persons (Bell and Sander, 2001; Brown et al., 1998; MacDonald et al., 2000; Sander and Shorvon, 1996).

#### *2.5.8 Age, seizure-type/epilepsy syndrome*

It is claimed that epilepsy is more common at the two extremes of life, that is among the younger and older age groups (Bell and Sander, 2002; Buchhalter, 2004). The prevalence increases with increasing age, decreases at middle age and then increases again after 60 years (Buchhalter, 2004). This trend was also manifested in a UK population-based study (Moran et al., 2004). It is also estimated that 50% of all cases occur under the age of one year and the majority of the remaining 50%, over the age of 60 years (Bell and Sander, 2001).

Specific seizure-types and syndromes are also known to be more prevalent within some age-groups (Brown et al., 1998; Buchhalter, 2004). With reference to the ILAE, 1981 seizure classification system, it has been suggested that generalized seizures are the most common type during the first year of life however, prevalence declines and remains fairly constant during childhood and adulthood (Buchhalter, 2004). By contrast partial (focal) seizures remains relatively constant until 65 years or over and increases again due to the prevalence of vascular diseases (Buchhalter, 2004). Contrary to this, other studies reported partial seizures to be more prevalent during childhood (Berg

et al., 1999). Also, the individual seizure types may or may not vary with age. In terms of generalized seizures, the vast majority of myoclonic seizures occur during the first five years and decline thereafter or if present at all may manifest in the form of juvenile myoclonic epilepsy (Buchhalter, 2004). Moreover, the frequency of generalized tonic-clonic seizures is relatively constant across all age groups. 'Absence seizures' are claimed to be rare during the first year but peak between the ages of five and ten and declines thereafter becoming uncommon after 30 years (Buchhalter, 2004). Also, complex and simple partial seizures which are common in adults are relatively constant within 5-50 years of age (Buchhalter, 2004). In the UK approximately 60% of people with epilepsy are reported to have tonic-clonic seizures (Brown et al., 1993). This includes: 20% with secondary generalized seizures; 20% complex seizures; 12% with mixed tonic-clonic and partial seizures; about 3% with simple partial seizures and less than 5% with absence seizures and myoclonic seizures (Brown et al., 1993). However, a study regarding the distributions of epileptic syndromes from hospital and epilepsy centre data revealed a pattern in relation to age. This pattern appears more apparent among the paediatric population (Buchhalter, 2004).

## 2.6 Mortalities in epilepsy

### *2.6.1 Life expectancy and mortalities in epilepsy*

Epilepsy is a potentially life-threatening condition and has been widely observed to carry a risk of premature mortality (Gaitatzis et al., 2004a, 2004b; Gaitatzis and Sander, 2004). It is claimed that life expectancy in people with epilepsy is said to be lower than in the general population especially, among individuals with newly diagnosed epilepsies (Gaitatzis et al., 2004a).

Overall, numerous studies have consistently reported a significant excess mortality in people with epilepsy compared with the general population (Cockerell, 1996; Cockerell et al., 1994; Forsgren et al.,



1996, 2005b; Hitiris et al., 2007; Lhatoo et al., 2001a; Mohanraj et al., 2006; Morgan and Kerr, 2002; Nilsson et al., 1997, 1999, 2001). Estimates are that there are two- to three-fold increases in Standard Mortality Ratio (SMR) among individuals with epilepsy compared with the general population (Cockerell, 1996; Cockerell et al., 1994; Forsgren et al., 1996, 2005b; Hitiris et al., 2007; Morgan and Kerr, 2002; Nilsson et al., 1997). Furthermore, for individuals with learning disabilities and epilepsy, mortality figures are estimated to be as high as five times more than the general population (Wilcox and Kerr, 2006). Although the causes of death may vary, the SMR for all causes of death (both in the community and hospital) in the UK are estimated to range from 1.6-3.6 (Lhatoo and Sander, 2005).

### *2.6.2 Factors affecting mortality rates*

In general, mortality rates are influenced by the methodologies adopted, thus making comparison difficult (Logroscino and Hesdorffer, 2005). The main methodological issue commonly reported relate to selections bias (Hitiris et al., 2007). For example there are biases associated with definitions, diagnostic accuracy, cohort size, incomplete data-follow up and inappropriate controls are all known to affect mortality estimates (Hitiris et al., 2007; Langan et al., 2005; Nashef et al., 2007; Nashef and Shorvon, 1997).

Furthermore, it is argued that due to stigma, many people living in communities with mild learning disabilities, may not be in touch with specialist epilepsy services (Wilcox and Kerr, 2006) and subsequently may not be diagnosed at all. This is reflective of inequalities in health service provision for people with learning disabilities, and has implications for communication in terms of content and context. It is argued that even when the epilepsy diagnosis is accurate, case ascertainment may be difficult (Sander, 2003a). Some people with epilepsy may refuse to seek medical care as a result of lack of information or the individual may be misdiagnosed (Sander, 2003a). The net result may be that death certificates do not mention epilepsy,

therefore affecting mortality figures (Hitiris et al., 2007; Janicki et al., 1999).

### *2.6.3 Risk factors for mortality in epilepsy*

Risk factors for mortality in epilepsy as mentioned earlier are dependent on the aetiology and the nature of the epilepsy (Hitiris et al., 2007; Lhatoo et al., 2001a; Morgan and Kerr, 2002; Nashef et al., 2007; Nashef and Shorvon, 1997; Nilsson et al., 1997, 1999). These factors may be grouped into: epilepsy related deaths; deaths from the pathology responsible for the epilepsy; and death from unrelated conditions (Hitiris et al., 2007).

Mortality rates in people with learning disabilities and epilepsy are said to be about five times higher compared with the learning disabilities population overall (Forsgren et al., 1996, 2005b). Furthermore, marked increases in mortality rates were reported in people with epilepsy and cerebral palsy (Forsgren et al., 2005b; Wilcox and Kerr, 2006). A study in a Swedish cohort reported an increased SMR of 5.0 in people with learning disabilities and epilepsy to a 5.8 in people with co-existing cerebral palsy (Forsgren et al., 1996, 2005b). Mortality and SMR are reported higher among children and younger adults but decreases with increasing age (Forsgren et al., 1996; Hitiris et al., 2007; Lhatoo and Sander, 2005). In a UK population-based study, the SMR was highest (6.6) during the first year of follow up for confirmed epilepsy and 5.1 for possible epilepsy, but declines to about half in the subsequent three years (Cockerell, 1996; Cockerell et al., 1994). However, when the 50-59 year age group was considered, the SMR was particularly high (about 8.6 for confirmed epilepsy and 6.6 for possible epilepsy) (Cockerell, 1996; Cockerell et al., 1994).

### *2.6.4 Cause-specific mortalities*

Generally, it is claimed that direct epilepsy-related causes of death are uncommon in the general population (Lhatoo and Sander, 2005) and in population-based studies (Lhatoo et al., 2001b). However,

epilepsy related causes of death account for about 24-62% of institutionally-based people with epilepsy, (Wannamaker, 1990 in:Lhatoo and Sander, 2005). Also, it is reported that about 30% of epilepsy-related deaths in adults occur among people with learning disabilities (Wilcox and Kerr, 2006). This may relate to cognitive and communication difficulties. Community-based studies also suggest that the cause of death varies and is dependent on the duration of the seizure disorder (epilepsy syndrome), the type of seizures and the presence of active seizures (Cockerell, 1996; Cockerell et al., 1994). However, unrelated conditions such as cerebrovascular disease, ischemic heart disease, neoplasia and pneumonia are known to be the most frequent causes of death among people with epilepsy (Hitiris et al., 2007; Lhatoo et al., 2001a; Nilsson et al., 1997, 1999; Shackleton et al., 1999, 2002). Several population-based studies in the UK have demonstrated that pneumonia is the commonest single cause of death in people with epilepsy (Cockerell, 1996;Cockerell et al., 1994;Morgan and Kerr, 2002). Psychiatric co-morbidities such as suicide and stress are known also to be a common cause of mortality among the epilepsy population (Morgan and Kerr, 2002;Yuen et al., 2007) but may be higher among learning disabilities populations.

#### *2.6.5 Epilepsy related deaths*

Epilepsy and seizure-related deaths are thought to be mostly due to: SUDEP, status epilepticus, suicide, aspiration, drowning and accident, remote symptomatic epilepsy and alcohol (Hitiris et al., 2007;Langan et al., 2005;Lhatoo et al., 1999b;Lhatoo and Sander, 2002;Nashef et al., 2007;Tomson et al., 2005). Others include; epilepsy surgery, vagus nerve stimulation, and mortality during pregnancy (Hitiris et al., 2007).

The cause of the mortality is said to be related to the cause of the epilepsy (Lhatoo and Sander, 2005). It is claimed that remote symptomatic epilepsy appears to carry a higher risk of death compared with the idiopathic/cryptogenic epilepsy (Cockerell, 1996;

Cockerell et al., 1994; Lhatoo et al., 2001a). However, the most frequently reported epilepsy-related cause of death is SUDEP (Hitiris et al., 2007; Tomson et al., 2005).

#### *2.6.6 Sudden Unexpected Death in Epilepsy (SUDEP)*

People with epilepsy are more likely than the general population to die prematurely and unexpectedly with no clear structural and pathological cause for their death (Hitiris et al., 2007; Nashef et al., 2007). Such deaths, classified as SUDEP (Nashef et al., 2007), account for a significant proportion of deaths in epilepsy (Forsgren et al., 2005b; Hitiris et al., 2007; Lhatoo et al., 1999b; Lhatoo and Sander, 2002, 2005; Tomson et al., 2005). SUDEP is said to be about 24 times more common in people with epilepsy compared with the general population (Ficker, 2000) and accounts for at least 500 deaths per year in the UK (Hanna et al., 2002). However, the issue as to whether and when to discuss SUDEP with people with epilepsy remains an ethical and a legal dilemma and continues to be debated (Beran, 2006; Beran et al., 2004; Hitiris et al., 2007). This has implication for people with learning disabilities and epilepsy who have cognitive and communication difficulties.

Consensual definition for SUDEP remains lacking (Tomson et al., 2005). Nashef and Shorvon referred to SUDEP as a sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning death in patients with epilepsy with or without evidence of a seizure and excluding documented status epilepticus, in which post-mortem examination does not reveal a structural or toxicological cause for the death (Nashef and Shorvon, 1997). SUDEP is the commonest cause of seizure-related death in refractory epilepsy (Hitiris et al., 2007; Pedley and Hauser, 2002) and may account for 10-50% of all reported deaths (Tomson et al., 2005). The precise incidence of SUDEP is not known due to methodological differences (Lhatoo et al., 1999a); however, SUDEP incidence is reported to be inversely proportional to the remission of seizures (Tomson et al.,

2005). A study in Glasgow, using the Western Infirmary epilepsy register of 6140 people with epilepsy, reported 11.7% of deaths attributed to SUDEP (Hitiris et al., 2007).

### *2.6.7 Risk factors for SUDEP*

Although the precise cause of SUDEP is not known, several risk factors have been identified (Monté et al., 2007). It has been widely reported that younger age groups (20-44 years) and poor seizure control appears to place individuals at high risk of SUDEP compared with older age groups (Ficker, 2000; Forsgren et al., 1996, 2005b; Mohanraj et al., 2006; Monté et al., 2007). SUDEP is said to be more likely to occur in those who also have neurological deficits or learning disabilities (Forsgren et al., 1996, 2005b; Hitiris et al., 2007; McGrother et al., 2001; Tomson et al., 2005; Walczak et al., 2001). Also, the relative risk of SUDEP is reported to be much higher in people with multiple learning disabilities (Nilsson et al., 2001). This could partly be due to the underlying co-existing conditions or the association between seizure frequency and SUDEP.

In addition, the presence of tonic-clonic seizures, polytherapy and an IQ of less than 70 were reported as independent risk factors for SUDEP (Walczak et al., 2001). Generalised tonic-clonic seizures have been widely reported in the vast majority of SUDEP cases (Bell and Sander, 2001; Langan, 2000; Langan et al., 2005; Monté et al., 2007; Tomson et al., 2005). However, this evidence is inconclusive since Hitiris et al found no association between SUDEP and generalised tonic-clonic seizures (Hitiris et al., 2007). Moreover, other risks factors for SUDEP include: high seizure frequency (Forsgren et al., 1996; Langan et al., 2005; Tomson et al., 2005), and early onset of epilepsy with a mean duration of seizures ranging from 15-20 years (Hitiris et al., 2007; Tomson et al., 2005). As mentioned earlier, people with learning disabilities are at higher risk of SUDEP since epilepsy in people with learning disabilities is difficult to treat and compounded with communication difficulties.

Furthermore, one of the central areas with relevance to this study is the association between SUDEP and the pharmacological management of epilepsy in particular, antiepileptic medications (Nilsson et al., 1997, 1999, 2001). Although, some commentators argue that antiepileptic medications are not high risk factors for SUDEP (Monté et al., 2007), it is asserted that effective treatment is crucial in minimizing the risk of SUDEP through enhanced seizure control (Tomson et al., 2005).

A number of drugs-related risks of SUDEP have been investigated. It has been observed that concomitant antiepileptic drugs use poses an increased risk of SUDEP (Nilsson et al., 1999; Tennis et al., 1995). In addition, there are reported inconsistencies regarding the role of polytherapy as a risk factor for SUDEP (Tomson et al., 2005). Monotherapy and duo therapy are reported to be associated with improved seizure control (Stephen and Brodie, 2002; Tiffin and Perini, 2001). While some studies have identified polytherapy as an independent risk factor (Moran et al., 2004; Walczak et al., 2001), other researchers reported to the contrary (Hitiris et al., 2007). Similarly, some studies suggest specific AEDs such as Carbamazepine and phenytoin to be associated with SUDEP (Timmings, 1998). Yet, other studies found no correlation between monotherapy of carbamazepine and phenytoin as risk factors for SUDEP (Hitiris et al., 2007; Nilsson et al., 1997, 1999, 2001). Moreover, high plasma concentration levels of polytherapy have been reported to be particularly associated with high risks of SUDEP (Ficker, 2000; Nilsson et al., 1999, 2001; Tomson et al., 2005). In addition, frequent dosage changes have also been observed as a possible risk factor for SUDEP (Nilsson et al., 1999).

Moreover, it is claimed that low blood concentration levels of AEDs, which could be due to non-compliance or poor concordance may be a risk factor for SUDEP (Ficker, 2000; Langan et al., 1998; Nilsson et

al., 2001). Non-adherence and poor seizure control are reportedly high among the epilepsy population in general (Jones et al., 2006; Tomson et al., 2005) but this could be considerably higher among the learning disabilities population due to cognitive and communication impairments (Whitten and Griffiths, 2007). Available estimates are that about 20% of people with learning disabilities have at least one seizure per year (Clark et al., 2001).

## 2.7 Information provision and the impact on seizures

Seizure control is the main goal for medical and nursing staff, as well as for people with learning disabilities and their carers. The ability to control seizures is an essential part of the management of epilepsy. The person with the epilepsy including their carers will need to have an understanding of the condition, be able to feedback information regarding seizures, medications and side effects (Kerr, 2001; Kerr and Bowley, 2001a). Effective communication is a key driver in this context. As discussed earlier, the prognosis of epilepsy is dependent on many factors, for example, the aetiology, age at onset, seizure frequency and the natural history of the condition and the influence of treatment (Bell and Sander, 2001; Sander, 2003a). It is generally believed that about 70-80% of people who develop epilepsy will go into long-term remission within the first five years (Bell and Sander, 2001; Sander, 2003b). However, community and institutionally-based studies indicate that 20-30% of newly diagnosed people with epilepsy do not enter remission (Bell and Sander, 2001). Furthermore, in the UK it is documented that seizures remain uncontrolled in about half of the people with epilepsy and impacting significantly on quality of life (Lhatoo and Sander, 2001; Lhatoo et al., 2001b; Moran et al., 2004). Uncontrolled seizures are associated with increased mortality and physical injuries and also a range of psychosocial morbidities, leading to a significant economic burden on the individual and their carers (Kwan and Brodie, 2007; Wilcox and Kerr, 2006).

The possibility of seizure reoccurrence is reported higher among people with symptomatic or cryptogenic epilepsies compared with those with idiopathic epilepsy (Kwan and Brodie, 2000). Also, the risk of seizure reoccurring is said to be greater in the first weeks or months after an initial seizure, with community-based people more likely to have a seizure than institutional populations (Bell and Sander, 2001). This observation is supported by other study findings which suggest that people with epilepsy who live in institutional settings have better seizure control when compared with those in community settings (Branford et al., 1998a, 1998b; Huber et al., 2005, 2007; Huber and Seidel, 2006). This may relate to limited support and poor communication leading to non-compliance. It is claimed that a multidisciplinary approach is key to effective epilepsy management (Kerr and Bowley, 2001b). Individuals who are based in institutions may be better supported by multidisciplinary staff to facilitate adherence to treatment and enhance seizure control. However, following implementation of revised social policies, in particular the advent of deinstitutionalisation, increasing numbers of people with learning disabilities and epilepsy are now residing in communities independently or supported by carers who may have varied or limited knowledge regarding epilepsy to support the service user (McEwan et al., 2007; Rasaratnam et al., 2004). This may have implications for communication between service user, carers and health care professionals. Community-based individuals with learning disabilities may also encounter significant barriers in accessing primary care services (Kerr et al., 1996) due to limited adaptive functioning and communication (Ouellette-Kuntz, 2005).

Moreover, the percentage of people with learning disabilities who achieve seizure freedom is reported to be lower than the epilepsy population in general (Kelly et al., 2004). People with learning disabilities are 20-30 times more likely to experience seizures compared with the epilepsy population overall (Espie et al., 2003; Moran et al., 2004; Scheepers et al., 2004). Furthermore, it is



claimed that about 20% of individuals with learning disabilities and epilepsy experience at least one seizure per month (Clark et al., 2001). This could be attributable to a number of factors as discussed further below.

### *2.7.1 Compliance/concordance*

The reported non-adherence to medications among the epilepsy population is similar to other conditions and ranges from 30-50% (Leppik 1990 in: Jones et al., 2006), but appears to be higher among the learning disabilities population (Scheepers et al., 2004; Tiffin and Perini, 2001). However, a study by Jones et al, in a population of 54 people with epilepsy reported 57% of them to be non-compliant with their medications and 57% had poor seizure control (Jones et al., 2006). Individuals with poorly controlled seizures had significantly higher numbers of seizures than those with well controlled seizures (Jones et al., 2006). An audit of 75 people with learning disabilities and epilepsy, revealed a mean seizure frequency of 52.3 per year with about 75% of them refractory to treatment (Jones et al., 2006; Scheepers et al., 2004; Tiffin and Perini, 2001). Poor compliance or non-compliance could be due to a range of factors such as communication difficulties, poor information or cognitive impairments

It is argued that compliance is a multivariate construct that is determined by the interplay of many factors (Rasaratnam et al., 2004). Some of these may reflect the complexities of treatment regimes, level of support and living circumstances (Rasaratnam et al., 2004). Other factors may relate to the role of service users as key drivers in the management of their own health (Scottish Executive, 2003b). A study by Buck et al, reported that failure to comply with antiepileptic drug treatment is common among younger people with epilepsy (Buck et al., 1997). Reported reasons include; lack of understanding of why it was necessary to adhere to treatment regimes and the level of information provision (Buck et al., 1997). This could be significantly higher among people who also have learning

disabilities. Emphasis is placed on how this information is provided in particular, for individuals with learning disabilities to promote understanding. Therefore, the information needs to be tailored to the individual's level in an accessible format to promote understanding. The importance of written information has been highlighted. It is claimed that adequate information provision leads to greater levels of compliance (Buck et al., 1997). Therefore, it may be of significant benefit if verbal information is reinforced with a written format. However, this has implications for the person with learning disabilities, who may have limited literacy skills, thereby limiting his/her access to health information (Ouellette-Kuntz, 2005). However, it is argued that written information should not be a substitute for a face to face interaction between health care professionals and service users. Service users may want to have open and honest discussions with their health professionals (Chappell, 1992;Chappell and Smithson, 1998).

Also, it has been noted that people reporting with side-effects were more likely to be non-compliant with their medications (Buck et al., 1997). However, non-compliance could be higher among individuals with learning disabilities for example, due to cognitive and communication impairments and also due to their susceptibility to unidentified side effects (Hannah and Brodie, 1998;Wilcox and Kerr, 2006).

Furthermore, it is argued that sufficient information given by health care professionals is not a guarantee of compliance. It is argued that people's compliance with medication regime is complex and dependent not only on understanding and following doctors' advice but also on how well it fits into the individual's life (Hunt et al, 1989 in:Buck et al., 1997). People with learning disabilities may make decisions based on their lifestyles and personal experience and may not just follow 'doctor's orders' (Buck et al., 1997). In addition, several views have been forwarded regarding what constitutes

success in health care delivery (Perkins, 2001). Symptom reduction as argued by some commentators is not an adequate index of success, and therefore is not a sufficient condition for enhanced quality of life (Perkins, 2001). While health professionals may be concerned with symptom reduction, the primary interests of carers may be in receiving information, having their roles as carers recognised and receiving the support and services that they need to facilitate their caring roles (Perkins, 2001; Wilcox and Kerr, 2006).

On the other hand, community-based individuals with learning disabilities may be concerned with choices in particular, regarding treatment options, empowerment and the involvement of the individual in the management of their health (Perkins, 2001; Scottish Executive, 2005). Scottish Intercollegiate Guidelines Network (SIGN) recommends that families and carers have a right to full, accurate and appropriate information to support their caring roles, including specific epilepsy types, its treatments and its impact on daily activities of living (SIGN, 2005). This reflects the National Institute for Clinical Excellence guidelines (NICE) that adults with epilepsy and their carers should be encouraged to manage their condition as much as possible (NICE, 2004). Several studies have reported that people with epilepsy want to know more about the causes of epilepsy, drug interactions and side effects and the avoidance of potential risks (Hart and Shorvon, 1995; Prinjha et al., 2005). It is well documented that people with epilepsy want more information about how to adapt to problems, in particular after initial diagnosis, more involvement in decision making, rapid access to local expertise and improved communication in a more interactive environment (Elwyn et al., 2003; Poole et al., 2000). They want clinicians who will among other things, have good communication skills (SIGN, 2005).

Carers play an integral role in supporting people with learning disabilities. Therefore, their involvement and information needs are essential to supporting their caring roles. It is claimed that carer

ability to sustain their caring role is crucial to patient well being (Espie et al., 1997). However, regarding people with learning disabilities, there are greater tendencies for communication breakdown because the communication processes are dependent not only on the person with the disabilities, who may have cognitive and communication impairments, but also on their carers (Kerr et al., 1996). In addition, healthcare providers may be dependent on carers for information to support diagnosis and management of epilepsy, in particular in community-based individuals with learning disabilities (Wilcox and Kerr, 2006). However, there is a paucity of research involving people with learning disabilities, in particular the individuals' views regarding what constitutes effective communication and what presents impediment to effective communication.

### *2.7.2 Pharmacological treatment of epilepsy*

Pharmacological treatment of epilepsy is the main approach in epilepsy management. However, it is argued that more than a third of people with epilepsy are not seizure free despite treatments with available medications (Duncan et al., 2006; Kwan and Brodie, 2007; Sander, 2004). Moreover, in the treatment of people with learning disabilities and epilepsy, issues relating to side effects of medications (see Table 1), and the impact of seizures as discussed above can be compounded by communication difficulties (Kerr and Bowley, 2001a; Kerr and Espie, 1997; Whitten and Griffiths, 2007). It is argued that the inability to communicate effectively, one's distress or discomfort makes diagnosis and treatment of health problems challenging for individuals with learning disabilities, their carers and health care professionals (Ouellette-Kuntz, 2005). In the vast majority of cases, epilepsy impacts on their lives and those of their carers. The person with the condition may require some form of medication. The need for effective communication between service users, carers and health care professionals is thus vitally important. Improved seizure control may lead to reduced morbidity and thus improve quality of life (Birbeck et al., 2002; Guekht et al., 2007; Harden et al., 2007). Also

pharmacological interventions with this population group present unique challenges due to the presence of other co-existing health conditions for example physical and psychiatric health conditions which may also require treatment (Prasher and Kapadia, 2006). In particular, the presence of cognitive impairment may require greater care in relation to appropriate use of antiepileptic drugs (Wilcox and Kerr, 2006). It is argued that the appropriate use of monotherapy versus rational polytherapy and also the use of broad-spectrum antiepileptic medication need to be considered (Alvarez et al., 1998; Kerr and Bowley, 2001a; Wilcox and Kerr, 2006) in order to minimise possible side effects. Monotherapy is arguably the recommended approach to treatment with some antiepileptic medication such as carbamazepine and phenobarbital (Huber et al., 2007). However, it is claimed that about 50% of people with epilepsy are managed with a combination of two or more antiepileptic drugs (AEDs) (Kelly et al., 2004). A study in a population of 675 people with epilepsy reported that 35.6% were seizure free with antiepileptic drugs (AEDs) and out of this 50.8% of seizure-free individuals were on monotherapy, 38.7% on duo therapy and 7.5% on triple therapy (Huber et al., 2005). However, in another retrospective study of 550 in-patients, 56.4% were free on a combination of two AEDs, 17.4% on monotherapy and 20.2% on triple therapy (Huber et al., 2007). This emphasises the need for effective communication between service users, carers and health care professionals to promote compliance.

Also, to minimize the incidence of adverse reaction and side effects, it is suggested that a monotherapy with a broad-spectrum of action may be of considerable benefit to individuals with learning disabilities (Alvarez et al., 1998). It is asserted that people with learning disabilities may also be more susceptible to adverse AED drug effects such as behavioural, cognitive or cerebral disturbance caused by some antiepileptic drugs (Alvarez et al., 1998; Beavis et al., 2007b). Therefore, it is argued that drugs that cause excessive sedation may result in further impairment in people with learning disabilities who

already have cognitive impairments, for example, Phenobarbital, primidone, benzodiazepines and vagabatrín are reported to be associated with behavioural problems (Alvarez et al., 1998). In a recent US study of 1394 people with epilepsy it was reported that 16% experienced psychiatric and behavioural side effects (Weintraub et al., 2007). This has further implications for communication regarding the choice for AEDs for individuals with learning disabilities, who are known to be more susceptible to psychiatric and behavioural disorders (Dykens, 2000;Emerson, 2003;Emerson et al., 2001).

Seizure prognosis can vary when treated with AEDs according to the epilepsy and seizure types. Whilst some seizure types and syndromes respond well to treatment with AEDs (see Table 1 for examples of AEDs), others appear to worsen seizures (Duncan et al., 2006). For example, Tiagabine and vigabatrin are contraindicated in the treatment of generalised-tonic clonic seizures (Duncan et al., 2006); whilst carbamazepine, Gabapentin, Oxacarbazepine, pregabalin, Tiagabine and vigabatrin are reported unhelpful in the treatment of myclonic seizures (Duncan et al., 2006; NICE, 2004). Epilepsy prognosis is said to be good in people with benign partial epilepsies and those with seizures which are triggered by specific precipitants (Duncan et al., 2006). Furthermore, prognosis is said to be effective for individuals with childhood absence seizures, epilepsy with non-specific generalized tonic-clonic seizures and some localization-related epilepsies (Sander, 2003b).

### *2.7.3 Non-pharmacological management of epilepsy*

Non-pharmacological options are considered only when drug treatment is unsuccessful. These options include curative surgery, palliative surgical procedures and ketogenic diet (Duncan et al., 2006;Stefan et al., 2001). Approximately 30% of people have pharmacologically refractory epilepsy in the UK (Beavis et al., 2007b; Lhatoo et al., 2003); in about half of these cases, epilepsy surgery is recommended as a means of achieving seizure remission (Lhatoo et

al., 2003). However, randomised controlled trials of non-pharmacological treatment in conjunction with AEDs remain lacking (Beavis et al., 2007a). Recent developments in neuroimaging have contributed significantly to the number of people undergoing epilepsy surgery. It is documented that 22% of neurosurgeons in the UK are reported to have performed epilepsy surgery (Lhatoo et al., 2003). However, people with learning disabilities are thought to have 'diffused' epileptogenic regions leading to debate whether or not they are suitable candidates for epilepsy surgery (Baker, 2001). Yet, the views of people with learning disabilities are unsolicited regarding epilepsy management.

**Table 1. Examples of some antiepileptic drugs**

| <i>Drugs</i>          | Main uses  | Common side effects   |
|-----------------------|--|---|
| <i>Benzodiazepins</i> | Status epilepticus, partial and generalised seizures   | Sedation, depression, confusion.  |
| <i>Carbamazepine</i>  | Partial seizures (with or without secondary generalisation) and primarily generalised tonic-clonic seizures. | Rash, dizziness, headache, nausea, teratogenesis, cognitive impairment  |
| <i>Ethosuximide</i>   | Absence seizures, continued spike-wave during sleep  | Nausea, drowsiness, headache  |
| <i>Phenobarbital</i>  | Partial and generalised seizures, status epilepticus, but ineffective against absence seizures.              | Hypotension, reparatory and sensorial depression, tiredness, poor memory  |
| <i>Phenytoin</i>      | Partial seizures, primarily generalised tonic-clonic seizures, status epilepticus                            | Headache, ataxia, somnolence, aggression, poor cognitive profile  |
| <i>Valporic acid</i>  | Partial and generalised seizures   | Weight gain, tremor, hair loss,   |
| <i>Felbamate</i>      | Severe epilepsies, particularly Lennox-Gastuat syndrome  | Nausea, vomiting, headache, dizziness, weight loss behavioural  |
| <i>Gabapentin</i>     | Partial seizures   | Dizziness, fatigue, weight gain, tremor, behavioural disorders, somnolence.                                     |
| <i>Lamotrigine</i>    | Partial seizures but may aggravate severe myoclonic epilepsy of infancy                                      | Dizziness, blurred vision, insomnia, headache, somnolence.  |
| <i>Levetiracetam</i>  | Partial and probably generalised seizures  | Dizziness, fatigue, headache, nervousness, behavioural disturbance  |
| <i>Oxacarbazepine</i> | Partial seizures and primarily generalised tonic-clonic seizures.  | Sedation, nausea, headache, fatigue, dizziness, ataxia  |
| <i>Pregablin</i>      | Partial seizures   | Dizziness, drowsiness, weight gain  |
| <i>Tiagabine</i>      | Partial seizures   | Dizziness, fatigue, somnolence, tremor, impaired concentration, depression.                                     |
| <i>Topiramate</i>     | Partial and generalised seizures   | Dizziness, impaired concentration, weight loss, behavioural disturbance   |
| <i>Vigabatrin</i>     | Infantile spasm (West syndrome), Partial seizures refractory to all AEDs.                                    | Somnolence, weight gain, fatigue, dizziness, depression, psychosis  |
| <i>Zonisamide</i>     | Partial and probably generalised seizures  | Fatigue, anorexia, dizziness, nausea, agitation, confusion, irritability, depression word-finding difficulties. |

#### 2.7.4 Summary of the review regarding the epidemiology

It is evident in the above review that there is no single definition for learning disabilities. Recently promoted definitions reflect the trend from medical to social models of disabilities. Definitions of learning disabilities have long been dominated by the discipline of psychology, with a characteristic emphasis on intelligence quotient (IQ). However, these definitions have been severely criticized by other schools of thought who argued that using IQ to define learning disabilities is unhelpful, discriminatory and should be abandoned (O'Brien, 2001;



Siegel, 1999, 2003; Simpson, 2007). Current definitions are based on social functioning approach and services contact. However, all definitions can be seen to have their limitations. The influence of the above literature review on the definition adopted in this study has been significant. As mentioned earlier, for the purposes of this project, *the learning disabilities population will be defined in terms of those people who are either receiving or eligible for learning disabilities services*. However, this definition is also bound to have some weaknesses. For example, the criteria for determining eligibility can be subjective and may be open to negotiation.

Overall, it is evident in this review that studies involving people with learning disabilities and epilepsy remain problematic and surrounded with controversies regarding definitions, classifications and diagnosis. These challenges appear to be largely mediated by communication difficulties however; this has not been fully investigated regarding people with learning disabilities and epilepsy. The review also revealed considerable variations regarding epidemiological findings among authors. These variations relate to differences in methodological approaches and case ascertainment (Bell and Sander, 2001; Sutherland et al., 2002) and may be regarded as a reflection of the challenges involving people with learning disabilities in research. Following social policies the population of people with leaning disabilities in the community has increased tremendously especially, individuals with mild learning disabilities who are leading independent lives in the community, albeit, supported by carers (McEwan et al., 2007;Rasaratnam et al., 2004). People with learning disabilities need to be empowered through communication to enable them to participate fully in community services. Furthermore, it is asserted that community-based residents are more likely to have a seizure compared with individuals in institutional settings (Bell and Sander, 2001, 2002;Huber et al., 2005, 2007;Huber and Seidel, 2006). This may relate to poor communication involving service users and health and social care professionals. Carers play a vital role in supporting

individuals with learning disabilities to manage their condition and their communication needs, together with basic knowledge and information regarding epilepsy, may be crucially important in their role.

Below are key findings from the review of epidemiological studies of learning disabilities and epilepsy as a further demonstration of the significance of communication involving people with learning disabilities and epilepsy and the need for this study.

#### *2.7.5 Key findings from the epidemiology literature review*

- It is estimated that there are about 7-30 people with mild to moderate learning disabilities in each GP practice across the UK (Emerson, 2001).
- Up to a third of all people with learning disabilities have epilepsy and up to a quarter of all people with epilepsy have learning disabilities (Lhatoo and Sander, 2001).
- The prevalence of epilepsy is said to be about 20-25 times more common among people with learning disabilities compared with the general population (Whitten and Griffiths, 2007).
- Seizures are more common among the younger and older age groups (Bell and Sander, 2001, 2002; Moran et al., 2004).
- People with learning disabilities are 20-30 times more likely to experience seizures compared with the general epilepsy population (Espie et al., 2003; Moran et al., 2004; Scheepers et al., 2004).
- The percentage of people with learning disabilities who achieve seizure freedom is reported lower than for the general epilepsy population (Kelly et al., 2004).
- Mortality especially sudden unexpected death in epilepsy (SUDEP) is said to be about 24 times higher in people with epilepsy compared with the general population (Ficker, 2000; Ficker et al., 1998).

- About 30% of epilepsy related deaths in adults occur among people with learning disabilities (Wilcox and Kerr, 2006).
- Mortality rates in people with learning disabilities and epilepsy are said to be about five times higher compared with the learning disabilities population over all (Forsgren et al., 1996, 2005b).
- SUDEP is said to be more likely to occur in people with learning disabilities or neurological deficit (Hitiris et al., 2007; McGrother et al., 2006; Walczak et al., 2001) and higher among those with multiple learning disabilities (Nilsson et al., 2001).
- Concomitant drugs use and low plasma concentration relating to polytherapy are associated with SUDEP (Moran et al., 2004; Nilsson et al., 1999, 2001). These could be due to non-compliance with medication (Langan, 2000; Langan et al., 2005; Langan et al., 1998; Nilsson et al., 1999, 2001).
- Non-adherence is reported higher among people with learning disabilities and this could be due to cognitive and communication impairments (Whitten and Griffiths, 2007).
- People with learning disabilities are more susceptible to unidentified side effects (Hannah and Brodie, 1998).
- Epilepsy management and issues relating to side effects can be compounded with communication difficulties (Kerr and Bowley, 2001a).
- People with learning disabilities are more vulnerable to neurotoxic effects caused by some antiepileptic drugs (Alvarez et al., 1998).
- Co-morbidities are reported higher among people with learning disabilities compared with the general population. People with learning disabilities are more susceptible to psychiatric and physical illness compared with the general population (Prasher and Kapadia, 2006; van Schrojenstein Lantman-De Valk et al., 2000).
- Alzheimer's dementia is said to set in 20 years earlier in people with Down syndrome than the general population (Lennox and

Eastgate, 2004). Estimated to occur at their mid-forties and early fifties (Gillberg and Soderstrom, 2003; Tyrrell et al., 2001).

- The diagnosis of epilepsy is dependent to a great extent on quality witness accounts from carers to enhance prognosis. It is estimated that 20-25% of people referred to specialist epilepsy units have a misdiagnosis of epilepsy (Kerr, 2001).
- However, community-based individuals who are not in touch with primary care services may not be diagnosed at all (Wilcox and Kerr, 2006).
- Most of the studies employ quantitative methodologies involving questionnaires, systematic reviews and randomised-controlled trials.
- Maladaptive or challenging behaviour (Bowley and Kerr, 2000; Smith et al., 1996) is reported higher among people with learning disabilities compared with the general population. However, people with learning disabilities may have limitations in communication, and challenging behaviour may well be a result of difficulty with communication (Kevan, 2003).

## 2.8 Communication

Communication is said to be a complex multidisciplinary concept and has been variously defined (Kraus and Fussell in: Higgins and Kruglandski, 1996). It consists of a complex composite of verbal and non-verbal behaviours linked together for the purposes of sharing information, messages, ideas and feelings (Arnold and Boggs, 2003; Hourcade et al., 2004; Rogers and Kincaid, 1981). Communication can take different forms. Individuals can communicate within themselves (intrapersonal) or with others (interpersonal). In health care settings, communication is said to be transactional in nature (Berne, 1961). It involves both the intrapersonal and interpersonal relationships (Donnelly and Neville, 2008). It is claimed that intrapersonal communication may be an internal activity which involves a possible source of actions or an

evaluation of the consequences of certain actions or activities but could also have some external expressions such as talking and writing (Berry, 2007). It is argued that intrapersonal communication consists of four key elements. These are: the core of self, needs and motivation, cognition and monitoring the reaction of others (Burton and Dimbleby, 1995).

The core of self relates to individual values, self image and individual personality differences. It is claimed that self-image is not only dependent on how the individual views him/herself but how they are seen and categorized by others (Berry, 2007). Self-image is made up of physical attributes such as body image, intellectual attributes and social and emotional components. These attributes together form the individuals' self-esteem which is a major factor in intrapersonal communication (Berry, 2007). Communication is also dependent on the individual's needs and motivations. There are reasons why individuals will initiate and decide whether to interact with others or not. In the context of this study, some of these reasons may relate to epilepsy and medication or may relate to the formation of social relationships. People with learning disabilities and epilepsy may have certain needs and motivation which drive the self to generate or interpret communication.

Furthermore, it is argued that cognition is the internal activity by which sense of the world is made (Burton and Dimbleby, 1995). Five cognitive processes are claimed to be involved in intrapersonal communication. These are decoding information, integration, memory, schemata and encoding the information (Burton and Dimbleby, 1995). The final element of intrapersonal communication involves monitoring the reaction of others to our communication to see what effect our communications may have on others.

Moreover, it is argued that the differences between one-way and two-way communication also reflects a degree of 'power' (Berry, 2007). It

is claimed that in one-way communication information or directives may be issued with little opportunity for the receiver to provide feedback.

This focus of communication reflects earlier models of communication forwarded by Shannon and Weaver (1949). According to this model information is selected by a 'source' and this is then encoded into a message. The message is then transmitted through a channel such as speech to a receiver who decodes or interprets the message and acts on it (Shannon and Weaver, 1949). However, this linear or one-directional form of communication is criticised for being too narrow because it does not allow the transactional nature of communication (Berne 1961). In contrast interpersonal communication involves interacting with two or more participants and all the parties being able to contribute to the communication process to reach a mutually shared understanding (Rogers and Kincaid, 1981). Hargie and Dickson (2004) define interpersonal communication as a process by which information, meaning and feelings are shared by persons through the exchange of verbal and non-verbal messages. This communication process involves essentially the following elements; 1. two or more communicators, 2. a message (i.e. the content of the communication), 3. The medium or the means through which the message is conveyed e.g. voice, body language, photos and technologies 4. The communication channels e.g. the link between the communicators 5. a code or a system of meaning shared by a group, 6. Noise e.g. environmental factors, 7. Feedback, 8. the context in which the interaction occurs or takes place (Hargie and Dickson, 2004).

This focus of communication reflects recent models of communication with the emphasis on process and a more transactional approach to communication. For example, Hargie's model of communication (1997) is based on three basic assumptions in that people act purposefully, they are sensitive to the effect of their actions and they

take steps to modify subsequent actions in the light of the information. This model argues that, due to the evolving nature of communication, all participants are senders and receivers of information at the same time. The model identifies six key elements of interpersonal communication. These are: the person-situated context, goals, mediating process responses, feedback and perceptions (Hargie, 1997 in: Berry, 2007). This author argues further that what takes place when people are engaged in communication relates to the particular attributes the individuals bring into the relationship. These include their knowledge, values, emotions, motives, attitudes and expectations as well as age and gender. The model, in addition to recognising the impact of the physical context on the interaction and the roles or tasks placed on the individual participants in the interaction, is also influenced by culture. This intercultural difference encompasses differences in both verbal and non-verbal communication (Berry, 2007). Other key elements of this model include the goals the individuals strive to achieve and also the mediating processes. Such mediating processes include various cognitive processes such as encoding, storage and retrieval of information, inferential processes and response generation (Hargie, 1997). However, these cognitive processes are claimed to be impaired in some individuals with learning disabilities; in particular, individuals with autism leading to communication difficulties.

Cognition and communication has been widely researched in cognitive psychology, in particular in relation to the 'theory of mind'. It is claimed that the theory of mind is the individual's ability to attribute certain mental states such as beliefs, desire, intention and knowledge with the recognition that these mental states are different from other individuals (Happé, 1993). However, it is claimed that some people for example individuals with autism, suffer from certain impairments in their abilities to attribute these mental states (Happé, 1993). It is argued that the ability to represent such mental states will require secondary or meta-representation but this appears to be lacking in

the autistic person's processing of a social situation. Therefore, autistic people have specific difficulties in the use of language for communication (Happé, 1993).

Communication in the health care setting is of crucial importance to the quality of life of the individual (van der Gaag, 1998). Effective communication is largely recognised as a key determinant of patient satisfaction, compliance and recovery (Chant et al., 2002). It is argued that effective communication can boost patient recovery whereas poor communication can be distressing to the patient and health and social care professionals (Hemsley et al., 2001). However, people with learning disabilities, irrespective of their levels of impairments, are more likely to encounter some form of communication difficulties compared with the general population (Kelly, 2002). McQueen et al estimated that 66% of people with learning disabilities have some form of communication difficulties (McQueen et al, in:van der Gaag, 1998). A survey in a social educational centre reported 81% of people with learning disabilities required support with their communication, 9.5% of these needs being non-verbal and 5.9% demonstrating low understanding (Law and Lester, 1992 in:Bartlett, 1997).

It is further claimed that communication with adults with learning disabilities is more challenging compared with the general population (McConkey et al, 1999). These communication difficulties are usually conceptualized to originate from the person with the disabilities (McConkey et al, 1999). Thus, researchers mostly focus on soliciting carers and health care professionals views regarding how to remediate these communication shortcomings (McConkey et al., 1999). However, communication is a two way process involving all the communication partners as senders and receivers of information, feelings or experiences (Hargie and Dickson, 2004); including those partners with learning disabilities.



Furthermore, it has long been assumed that the communication style of adults with learning disabilities are less susceptible to change and therefore any modifications to communication are more likely to be driven by the more able persons who are more adaptable to meeting the communication needs of the individual (Chatterton, 1999; McConkey et al., 1999). Bartlett & Bunning, cited in Bartlett (1997), commented on the need for staff to recognise and make adaptive changes to meet the communicative 'acts' of service users. However, other schools of thought forwarded the view that everyone can communicate; even people with severely impaired communication disabilities are able to communicate quite effectively if given the right support and facilitation (Kovarsky et al, 1999 in: Hemsley et al., 2001). As mentioned earlier, effective communication is a mutual endeavour with the following requirements; an intention to share, a desire to reach common understanding, active listening by the receiver, understanding, by all parties of the influences of background culture, the commitment to use accessible language and the mutual willingness to ensure the message is understood (Higgs et al., 2005). However, this focus of communication as a two-way process has not been reflected in research that investigates communication regarding people with learning disabilities and epilepsy, in particular, service users' views regarding communication remain unsolicited as discussed in the next section. Therefore, there is a need for a more holistic investigation into the views and experiences of people with learning disabilities and epilepsy, in order to identify and/or reduce impediment to communication.

As mentioned earlier, the diagnosis and management of epilepsy is associated with communication difficulties (Whitten and Griffiths, 2007). It is claimed that missed diagnosis of epilepsy remains high among the general population and the diagnosis of seizure type can be extremely difficult among individuals with learning disabilities (Whitten and Griffiths, 2007). Thus accurate diagnosis is said to be partly dependent on the availability of witnessed accounts, for

example from carers (Sander, 2003a; Sander and Shorvon, 1996). In addition, the individual who takes medication to control seizures requires effective communication with both carers and health professionals with regard to compliance and adverse effects of medication.

### *2.8.1 What is known regarding research involving people with learning disabilities?*

Overall, communication research regarding people with learning disabilities focuses largely on meeting and developing health and social care staff communication needs and skills (Balandin et al., 2007; Bradshaw, 2001; Graves, 2007; Jones, 2000; McConkey et al., 1999; Pointu and Cole, 2005; Purcell et al., 2000). To a significant extent, communication studies regarding people with learning disabilities are more common among child populations (Bradlow et al., 2003; Horowitz, 2006; Kaiser, 2007; Wetherby et al., 2007). Also, studies that include adults are based on institutional or residential settings and mostly include people with severe to profound learning disabilities who have more complex communication needs (Bradshaw, 2001; Cegala, 2006; Jones, 2000). However, community-based adults with mild learning disabilities may have different communication needs and expectations but this focus has received little attention. In particular, at the time of writing, there is no single study that has investigated the views and experiences of people with learning disabilities and epilepsy regarding communication. Studies that investigate the individuals' perspectives regarding epilepsy often fail to distinguish the learning disabilities from the non-learning disabilities populations (Bautista et al., 2007; Chappell, 1992; Chappell and Smithson, 1998; Elwyn et al., 2003; Ismail et al., 2005; Paschal et al., 2007; Poole et al., 2000; Rätty et al., 2007). The service users' views regarding communication are often not reported or investigated. In particular, the presence of epilepsy can impact significantly on communication. Therefore, an important aspect is missing as communication is a two-way process.

The epidemiology of learning disabilities and epilepsy demonstrates the challenges confronting research involving people with learning disabilities, and the crucial role of communication. Carers play a fundamental role in supporting the individual to access social and primary care services. Therefore, it is prudent to investigate how communication is transacted involving the service user and also the service user's perspective regarding communication with health and social care professionals. Previous research has highlighted carers' needs for support regarding information and how to facilitate access to community services for people with learning disabilities (Hubert, 2006). In addition, carers' knowledge and information needs regarding epilepsy may influence their communication with service users and health care professionals. This will be discussed later in this section. However, there is lack of research on communication regarding people with learning disabilities and their carers; in particular, the individuals' perspectives regarding communication, to determine what constitutes effective communication and above all how communication may be maximised (van der Gaag, 1998).

### *2.8.2 Key issues regarding communication with people with learning disabilities and epilepsy*

Relevant key communication issues regarding people with learning disabilities may relate to the communication mode and medium, the communication context or setting (including the co-existing epilepsy), and the interpersonal skills of the individual. These will be discussed below.

#### Communication mode and media

##### *Comprehension: Verbal and non-verbal communication*

It is argued that although meanings can be conveyed in many different ways, verbal language is considered as primary in most interactions (Berry, 2007). It is claimed that verbal language is so pervasive that every human group that has been studied has a lexicon

of words and meanings (Berry, 2007). Verbal language is used to generate meanings and ideas and express feelings, and for developing and maintaining relationships (Berry, 2007). Verbal language can be spoken, written or both. It is argued that traditionally, verbal and non-verbal communication have been studied separately as though they are independent however, they are co-occurring and interrelated phenomena (Jones and LeBaron, 2002). It is asserted that during communication, especially face-to-face interaction, vocal and visible behaviours are typically coordinated in ways that provide for their mutual performance (Jones and LeBaron, 2002). When people are engaged in a communication, they also locate their bodies, assume various postures, direct their eyes and perhaps move their eyes altogether in an interactive event (Jones and LeBaron, 2002). However, most people with learning disabilities have difficulties in comprehending at some level and may rely on other forms of communication (Kelly, 2002).

People with learning disabilities may want to engage face-to-face with their carers and health care professionals but may have difficulties with physical articulation of the words, impaired cognition and therefore may employ more non-verbal forms of communication. Therefore, a communication gap is likely to exist between staff who communicate mostly through a verbal mode and individuals with learning disabilities who may have communication impairment. It is claimed that when there is a mismatch between the verbal and non-verbal messages it leads to a phenomena known as 'social leakage' (Berry, 2007). This observation was reflected in a study by McConkey and colleagues who reported inequalities in communication exchanges between staff and service users with staff relying more on verbal communication strategies (McConkey et al, 1999). A similar study by Bradshaw regarding care workers' perceptions of understanding of people with learning disabilities communication exchanges revealed that they appear to underestimate their use of verbal communication and overestimate their use of non-verbal communication (Bradshaw,

2001). Staff were also more likely to use complex language leading to unrealistic opportunities for service users to participate in the communication exchanges (Bradshaw, 2001). The findings also indicate a mismatch between the reported level of understanding of the service user and the level of complexity of the language used (Bradshaw, 2001). Other authors reported that care workers often misinterpret the levels of understanding of adults with learning disabilities (Banat et al., 2002; Bartlett, 1997; McConkey et al., 1999; Purcell et al., 2000) and that staff often fail to take into account the communication needs of individuals with learning disabilities (Bradshaw, 2001). An average of 45% of communication 'acts' were reported to be outside the understanding levels of service users (Bradshaw, 2001).

People with learning disabilities may require sufficient time to communicate, however research findings suggest that health and social care professionals are four times more likely to initiate a communication 'act' compared with service users (Bradshaw, 2001; McConkey et al., 1999). Verbal communication by staff was also reported to be more prevalent irrespective of the service users' communication methods (Bradshaw, 2001; McConkey et al., 1999). There was also reported lack of augmentative and alternative communication strategies (McConkey et al., 1999). Although it is claimed that verbal communication may be widely recognised, research findings have indicated that the non-verbal component accounts for up to 80% of the content or meaning that is conveyed in face-to-face interaction (Berry, 2007). Other estimates are that about 55% of all communications are through body language, 38% via voice tonality with only 7% of communication which relies on the actual spoken words (Donnelly and Neville, 2008).

There is also a high prevalence of communication difficulties among people regarded as having 'challenging behaviours' where that challenging behaviour has a communication function (Bradshaw,

1998). Ferris-Taylor (2003) endorses the view that challenging behaviour may be an attempt to communicate a message. Furthermore, it is claimed that poor communication skills may also result in maladaptive behaviours that pose a challenge to health care professionals and carers (Ouellette-Kuntz, 2005). It is suggested that professionals working with people with learning disabilities should be aware of this and learn to recognise a range of behaviours as possible forms of communication, thus adopting a generous definition of communication (Kelly, 2002).

### Communication contexts and functions

The purposes or functions of service users' communications with health and social care professionals may differ. Communications regarding social issues are reported to be less frequent; also care workers' and service users' interactions are reported to be more functional in nature than social interactions (Bradshaw, 2001). The communication needs of people with learning disabilities and epilepsy may also relate to epilepsy and medication or may relate to psychosocial needs. Their communication needs and expectations during a medical encounter with healthcare professionals, for example, may differ from their communication needs with carers.

Furthermore, the relationships between disability, stigma and deviance have been reported extensively in the literature (Goffman, 1963; Susman, 1994). It is argued that individuals' experiences of disability have been influenced by perceptions of negative difference (deviance) and their evocation of adverse or punitive response (stigma). Although this study is not focused on stigma, it is claimed that stigmatised individuals adopt a range of strategies to cope with their condition including avoidance of social encounters (Susman, 1994) and this will influence communication with carers and health care professionals. In addition, the presence of co-existing epilepsy and its association with stigma is reported in the literature (Ablon, 2002) and may further compromise communication.

### *2.8.3 Communication in the context of healthcare*

Effective communication during a medical encounter is dependent on certain essential characteristics of both the patient and the health professional. For example differences in interpersonal relationships and communication skills, e.g. listening, empathy and the service user involvement, have been reported to influence health outcomes (O'Gara and Fairhurst, 2004). Therefore, skilful application of these interpersonal skills is crucially important to promoting compliance and health outcomes.

#### Interpersonal skills

There is a growing body of knowledge which supports the use of a 'patient-centred' approach to health consultation (O'Gara, 2004). It is claimed that a patient-centred approach places the patient and their cares and concerns at the heart of the interaction (O'Gara, 2004). It is built on the philosophy that the patient is not a passive recipient of care and recognises the importance of patient knowledge and experiences and uses it to guide the interaction. Langewitz et al (1998, p.230) define 'patient-centred' communication as 'communication that invites, encourages the patient to participate and negotiate in decision-making' (Langewitz et al., 1998). It is asserted that empathetic communication involves a thorough understanding of the patients' perspectives and this has the potential to motivate individuals to communicate leading to adherence and improved quality of life (Ong et al, 2000). Furthermore, patients have identified positive outcomes with healthcare professionals who communicate empathy (Travaline et al., 2005). Empathetic communication involves eliciting and exploring feelings, reflecting, using silence and listening to what the patient is saying but also what they are unable to express verbally (Ong et al., 1995; Ong et al., 2000). It is argued that patients' trust in their healthcare providers is essential to their emotional disclosure and that trusting relationship is nurtured in effective communication (Martin et al., 2005). Communication is also

said to be enhanced through familiarity with the health care providers, and when patients believe their health professional is someone who can understand their unique experiences as patients and who can provide them with reliable information and honest advice (O'Malley et al., 2002).

Good listening skills have also been associated with positive outcomes. Active listening by health care professionals is known to facilitate communication (O'Gara and Fairhurst, 2004). It is claimed that active listening includes a set of non-verbal skills that signifies to patients that the health professional is listening. These include, leaning forward; being silent and using smiles and nodding to encourage further disclosure and exploration of patient experiences (Branch and Malik, 1993). To a significant extent, certain demographic features are reported to influence the individual communication skills. In particular, studies have reported gender to play a key role in relationship building and communication. For example, female doctors' interaction in medical encounters average two minutes more than males' interactions and female physicians are reported to engage in more patient-centred communication than their male colleagues (Roter et al., 2002).

### Compliance and communication

Patients' non-compliance to treatment decisions is a growing concern among patients, carers and practitioners with significant socio-economic burdens on the individuals (Martin et al., 2005). Patients' non-compliance with treatment regimes has been widely researched and reported in the literature (DiMatteo and Reiter, 1994; Martin et al., 2005). Effective communication is an important variable to treatment adherence and has particular relevance to people with learning disabilities who are taking medication to control seizures (Harrington et al., 2004). It is claimed that people with learning disabilities are more likely to be non-compliant compared with the general population (Jones et al., 2006) due to cognitive and



communication impairment. However, it is argued that health management has many stages and issues regarding compliance could arise at any of these stages (Vermeire et al., 2001). Non-compliance could be referred to as a refusal to seek health care, non-participation in health management or failure to follow doctors' instruction (Vermeire et al., 2001). It may also take other forms for example, the information or advice given to people by their health care professionals is either misunderstood, administered wrongly, or the information is lost or ignored completely (Ong et al., 1995, 2000). However, these may all relate to poor communication in terms of how the information is provided. Thus, effective communication may play a crucial role in promoting compliance with health management.

### Information provision

Furthermore, people with learning disabilities are more likely to demonstrate poor literacy skills compared with the general population (Ouellette-Kuntz, 2005). It is argued that health literacy is the extent to which people have the ability to obtain, process and understand basic health information (Hironaka, 2008). In particular, people with learning disabilities may have limited vocabulary and limited understanding of written and spoken words. In a health care setting, many different words or phrases are used to describe the same thing, some being used metaphorically or linking to a particular context or experience (Kelly, 2002). The frequency of use of 'medical language' over the use of every day language has received significant commentary (Ong et al., 1995). It is argued that there is the tendency for health professionals to use the same medical vocabulary and complex sentences when communicating with patients as they would when engaging in communication with their colleagues (Houts, 2006). People with learning disabilities need information in a format that they can understand: in simple, clear and non-technical language free from jargon, and tailored to the communication needs of the individual (Martin et al., 2005).

Moreover, as mentioned earlier the understanding of information by people with learning disabilities is dependent on the format and how the information is presented (Rodgers and Namaganda, 2005). Studies suggest that misunderstanding of information is significantly high within the general population (Martin et al., 2005) and this could even be higher among people with learning disabilities due to communication and cognitive impairment. A study in the general population found that 42% misunderstood the information that the medication should be taken after meals, 25% misunderstood their next appointment date and about 60% were unable to read and understand information regarding informed consent (Williams, 1995). Efficient time management may contribute to the quality of the information provision and the success of the communication encounter. It is claimed that people with learning disabilities and epilepsy may require more consultation times with their health care professionals to discuss their treatment options (Prinjha et al., 2005).

#### Information and recall

Another significant factor is the ability to recall information provided by health and social care professionals (Ong et al., 1995). It has been reported that forgetfulness to take medication is common among the general population and could be higher among people with learning disabilities due to cognitive impairment (Martin et al., 2005). It is argued that even when the information is well communicated and the understanding is initially high, much of it could be forgotten within minutes after leaving the encounter (Shemesh et al., 2004). The use of pictures in health communications has been widely applied. Whilst all patients can benefit from the use of pictures, individuals with low literacy skills especially, people with learning disabilities are more likely to benefit the most (Houts, 2006). Face-to-face communication is considered an effective way of sharing information but it is argued that often the information provided by health and social care professionals is more than the patient can retain (Houts, 2006). It is further claimed that verbal communication alone may have negative

aspects (Demir et al., 2008), since it may easily be forgotten. Therefore, when information is reinforced with written materials including illustrations it may enhance recall (Demir et al., 2008;Rodgers and Namaganda, 2005). However, this demands the individuals with learning disabilities to at least be able to understand written information (Ouellette-Kuntz, 2005).

### Service user involvement

Involving the patient in their care is pivotal to any successful health encounter (O'Gara and Fairhurst, 2004). Partnership has been identified as a key determinant of patient satisfaction and the involvement of the service user in decision-making is important to promoting concordance (Winefield et al., 1995). Studies have shown that patient satisfaction and adherence are ultimately linked to their involvement in the treatment (Martin et al., 2005). It is argued that patients who feel their healthcare professionals communicate well with them and actively encourage them to be involved in their own care are more likely to adhere to treatment (O'Marley et al, 2002). Professional-led consultations which place the patient as a passive recipient of information appear to be outmoded. Doctor-patient relationship is seen as a partnership where the patient plays a key role in the delivery of health services (DiMatteo and Reiter, 1994;Ong et al., 1995). It is argued that 'patient-centred medicine' is a model which comprises the following: exploring both illness and disease experience; understanding the whole person; finding common ground; incorporating prevention and health promotion; enhancing the doctor-patient relationship and finally being realistic about time and resources (Stewart, 1995). Furthermore, the philosophy of collaborative interpretation emphasises that the relationship between the healthcare professional and the patient is reciprocal (Young and Flower, 2002). It enables the patient to express their concerns or conditions in the context of their own life and to share their experience with the healthcare professional in the spirit of mutuality (Flower and Young, 2002). This challenges health and social care

professionals to develop a reciprocal relationship where the exchange of information, identification of problems and the development of solutions to those problems are shared with the service user where they can input in the communication exchanges (Young and Flower, 2002). It is claimed that when patients see themselves as partners and as problem solvers it may motivate them to exchange information more freely and they are more likely to adhere to their treatment recommendations (Young and Flower, 2002). It is anticipated that health and social care professionals who want to maintain this relationship will tend to act in ways that encourage the patients to be actively involved in their own care. However, people with learning disabilities are more likely to acquiesce during conversations (Grove et al., 1999). There is a need to encourage and support people with learning disabilities to explore and express their views and feelings.

Nevertheless, it is argued that the patient's understanding of their health professional's recommendations regarding treatment is not a guarantee of compliance with the treatment regimes but is also dependent on the individual patient attitudes and beliefs (Martin et al, 2003). This reflects social cognitive models of health behaviour for example the Health Belief model (Rosentock, 1974) and the Theory of Planned Behaviour (Ajzen, 1988). These models attempt to explain and predict the influence of certain health behaviours. Primarily the models are based on the premise that people may make health decisions on the basis of their beliefs. It is asserted that individuals' choices regarding different courses of action are influenced: subjective views that a given action will lead to a set of expected outcomes; and evaluation of the impacts of the outcomes. This means that people reflect over a particular course of action before deciding whether or not to engage in particular health behaviour (Berry, 2007). Community-based people with learning disabilities may want to lead an independent life and to adopt a more consumerist perspective regarding the services they receive. Therefore, they need to have full access to health information including risks and benefits

to enable them to make informed decisions regarding their own health.

## 2.9 Communication facilitators

Accessible communication plays an essential part in providing choices by removing communication barriers which might otherwise inhibit individuals from accessing services or getting the information they require. Communication can be made accessible in a number of ways. For example, the use of Talking Mats to elicit the views of people with learning disabilities has been widely applied in research (Murphy et al., 1998; Murphy, 2006). Also, the role of photographs and pictures to improve health communication has received significant attention (Hourcade et al., 2004; Houts, 2006; Katz et al., 2006) and has been associated with qualitative studies in particular, among people with learning disabilities (Creswell, 2007). Other authors argued that it is not enough to use simple language through the use of verbal communication but there is the need to supplement that with a variety of supports including the use of pictures and cue cards (Lewis and Porter, 2004).

### *2.9.1 Augmentative and Alternative Communication (AAC)*

Acquiring information and making choices can be difficult for many people with learning disabilities depending on where and how the information is provided (Owens, 2006). A person with learning disabilities may have limited vocabulary, have difficulty understanding and will need information in a format they can access. An Augmentative Alternative Communication (AAC) system is a 'package' of communication facilities that makes up the 'total communication' resource for an individual with learning disabilities (Kelly, 2002). It is claimed that the AAC has undergone remarkable transformations since its introduction in the 1960s, for example the nature of assessment has transformed from the reliance on criteria, in which persons are required to demonstrate eligibility for the AAC by

attaining certain prerequisite skills, to the current universal model, which is based on the premise that anyone can communicate and benefit from the AAC system (Hourcade et al., 2004). The AAC system of communication may be categorised into two: 1. the unaided component which does not depend on any external communication device for the production of expressive communication for example, sign language, facial expression, gestures, and non-symbolic vocalizations (Hourcade et al., 2004); and 2. the aided systems which require devices for the production of expressive communication, for example the use of picture communication boards, and voice output machines (Beukelman, 1998).

Following technological advances, sophisticated computers have led to the development of user-friendly communication tools with voice output mechanisms in particular, for people with severe communication difficulties (Hourcade et al., 2004). It is argued that the development of a comprehensive vocabulary resource is central to most AAC systems (Graves, 2000). For example resources such as Makaton (Walker, 1987) and Boardmaker signs (Mayer-Johnson, 1992) have been widely used in supporting people who have communication difficulties to make information more accessible for them. It is claimed that accessible communication means designing information that is easier for everyone to use. Information can be empowering if it is made accessible for the individual (Owens, 2006).

### *2.9.2 Communication environment*

It is asserted that if the communication difficulties of adults with learning disabilities are to be understood, it is necessary to look beyond their communication skills and their abilities to use these skills, to consider relevant receptive and motivating communication environments to facilitate communication (Kelly, 2002). Furthermore, it is argued that involving people with learning disabilities in communication is dependent to some extent on the abilities of others to create effective opportunities for communication (Sigafoos, 1999).

For example, individuals with limited speech may require augmentative and alternative communication interventions as discussed above (Sigafoos, 1999). Although a communication opportunity is difficult to define, in this study it refers to any intervention that facilitates communication. This ranges from a consideration of the physical communication environment for example regarding noise and layout, the provision of choices. It is claimed that people need to be aware that choices are possible and available (Kelly, 2002) for them to access if they so wish. However, it is argued that choices are often pre-empted especially when the individual has a communication difficulty (Kelly, 2002). In this context, service users, carers and healthcare professionals need to be aware of what choice means to service users to enable them to make informed decisions affecting their daily living. Also the social models of disabilities discussed earlier suggest that disability results from barriers imposed by society. Therefore, the promotion of social models of disabilities may lead to the creation of opportunities for communication by removing communication barriers.

### *2.9.3 Training needs for health and social care professionals*

As mentioned earlier, following the advent of deinstitutionalisation in the 1990's, the population of people with learning disabilities in the community increased substantially (Bradshaw, 2002). However, community placement in itself is not necessarily an indicator of good health or improved quality of life. In fact, it is claimed that there may be worsening of health for people with learning disabilities in communities due to limited resources and skills (Pointu and Cole, 2005). A high percentage of people with learning disabilities and epilepsy who live in the community may be supported by staff with little or no training regarding communication and/or epilepsy and this may have implications for their abilities to provide adequate support for service users (Graydon, 2000; Pointu and Cole, 2005). Although many barriers to the provision of health care have been commented upon, a major barrier to the access to appropriate health services has

been identified as inadequate communication between the service user and health and social care professionals (Lennox et al., 1997; Ziviani et al., 2004). A study regarding general practitioners' perceptions regarding barriers and solutions to the provision of care for people with learning disabilities found that communication difficulties and problems in obtaining patient histories stood as the most important barriers (Lennox et al., 1997). The study found 85% agreed that communication difficulty was a barrier to quality health care and 80% agreed that poor communication between GPs and other health care professionals often limited the health care provided for people with learning disabilities (Lennox et al., 1997). Overall, 93% agreed that they would be able to provide better care if they undertook further education and training (Lennox et al., 1997). As it is more than a decade since this study was reported, the findings may not reflect contemporary practice; the focus regarding training and other educational needs might have changed. It is claimed that communication intervention programmes have shifted from working with individuals with disabilities to providing training interventions for family carers or paid carers and professionals (Bloomberg, 2003; Bradshaw, 2000). A recent study reported that communication interventions for carers is associated with positive outcomes (Kyle et al., 2009). Nevertheless, communication is a two way process and the service users views are essential to gaining a holistic understanding of communication in this context.

#### *2.9.4 Carer knowledge regarding epilepsy*

Carers are the immediate source of contact for people with learning disabilities; they may have reliable sources of information regarding the service user. They are more likely to witness a seizure. Also, because the individual may not remember and accurately report information regarding seizures, witness accounts from carers may be of great value in this regard. Therefore, carer knowledge and understanding of the types of seizure is essential as it may facilitate communication between service users and health care professionals.



Carers may also serve as advocates (with consent) for individuals with learning disabilities and epilepsy, to provide reliable information regarding the service user in relation to medication, to inform further treatment decisions. Therefore, it is imperative that carers' basic understanding of epilepsy is developed and their overall information needs regarding epilepsy are addressed as this will enhance communication with health care professionals. This may lead to positive epilepsy prognosis. However, even in the time course of the current study, concerns have been expressed by social care staff and healthcare organisations regarding the support of people with learning disabilities and epilepsy during emergency situations in community settings in the event of serial or prolonged seizures (Pointu and Cole, 2005). Furthermore, a significant consideration is the presence of side effects from antiepileptic medication. People with learning disabilities may be unable to identify or communicate medication side effects (Wilcox and Kerr, 2006) and may require their carers' support in order to communicate important information to their health care professionals.

#### *2.9.5 Key findings from the communication literature review*

The review above revealed numerous gaps in the literature regarding communication involving people with learning disabilities. In particular, there is lack of research that investigates the views and experiences of people with learning disabilities. To the best of the researcher's knowledge, there is no single paper that looks at similar aspects to this study.

Key findings that inform the need for this study include:

- Studies which investigate the extent of contact between health care professionals and people with learning disabilities focus on staff communication skills and needs. The focus has predominantly been based on staff views and the development of their skills regarding communication with people with learning

disabilities to the neglect of the service users' views and experiences. Thus, an important aspect of the process is missing as communication is at least a two way process.

- The few studies that reported service users' perceptions and views regarding epilepsy mostly exclude or fail to distinguish between the learning disabilities and the non-learning disabilities populations.
- The majority of communication studies regarding people with learning disabilities and epilepsy have been based on child populations. However, this may differ from the communication needs and expectations of adults. When adults with learning disabilities are included, often they are recruited from institutionally-based individuals who have severe to profound learning disabilities and more complex communication needs. Thus these findings are not applicable to adults with mild learning disabilities and epilepsy living in the community who may have different communication needs and expectations.
- A significant number of these studies employ observations in the form of video-recording and quantifying the frequencies of verbal and non-verbal forms of communication but the service users' experiences and views have not been solicited for example, through other qualitative methods.

## Chapter 3: Paradigms and Methodologies

### 3.1 Introduction

This chapter will focus on the following: 1. Overview of research involving people with learning disabilities to inform the methodology for this study 2. Discuss the qualitative approach and its relevance to this study 3. Provide the philosophical underpinning utilized in this study and 4. Describe the design and the methods used in this study.

### 3.2 Overview of learning disabilities research

It is argued that the development of research involving people with learning disabilities is fairly recent (Oliver, 1992; Walmsley, 2001). Studies which involve people with learning disabilities in the research process are mostly classified as 'inclusive research' (Walmsley, 2001). These 'inclusive research' studies are either participatory or emancipatory in nature where people with learning disabilities are involved in the study (Walmsley, 2001). It is argued that until the 1960s, little or no research had tried to access or include the voice of people with learning disabilities (Edgerton, 1967 in:Walmsley, 2001). It is claimed that research involving people with learning disabilities has been dominated by the positivists where people with learning disabilities are tested, counted, observed, described and often pathologised (Walmsley, 2001). Furthermore, it is argued that the focus of such positivists is on propositional or experimental methods to test hypothetical generalisations (Lin, 1998). However, there has been no attempt to include the service users' subjective or interpretive views or perspectives regarding the services they receive (Walmsley, 2001). In this 'quantitative' approach of inquiry, people with learning disabilities are passively involved in research and the research is carried out *on* them rather than *with* them (Kiernan, 1999).

It has long been observed that researchers have the potential to exploit vulnerable groups and may lead to their disempowerment and oppression (Swain, 1998). For many research studies involving people with learning disabilities it is argued that the researcher is located either on the side of the disabled person or the oppressor (Barnes, 2003; Oliver, 1992).

Until recently, people with learning disabilities have not been viewed as capable of discussing and understanding research ethics and this has strongly influenced their participation in research studies (Nind, 2008). Following the advent of inclusive research, influenced by the principles of the social model of disability (Oliver, 1992), this trend has changed and people with learning disabilities are engaged in research at various stages. Recent studies demonstrated that people with learning disabilities are not only capable of consenting to a research study (Cameron and Murphy, 2007; Young and Chesson, 2006), give their views on health issues (Young and Chesson, 2006) but can play diverse roles in research studies. For example as co-researcher (March, 1997), interviewers (Williams, 1998 in: Walmsley, 2001), as advisors (Stalker, 1998) and can determine research questions on health risks (Young and Chesson, 2007). It is now widely accepted that the individuals are the best authorities of their own lives, experiences, feelings and views (Goodley, 1996). People with learning disabilities have the right to be consulted and be involved in research which is concerned with issues affecting their lives; and the quality and relevance of the study is improved when people with learning disabilities are closely involved (Stalker, 1998). The scope of research involving people with learning disabilities in research has increased significantly, particularly in the 1980s (Flynn, 1986 in: Kiernan, 1999) with the adoption of more qualitative approaches as the methodology of choice for people with learning disabilities. Kiernan, commented that the goal of a qualitative research is to 'ground' studies based on the experiences and views of participants (Kiernan, 1999).

Nonetheless, the extent to which people with learning disabilities are involved in research has received widespread criticism. It is argued that even in qualitative studies it is the researcher or the funding body who determines the research question; and the researcher collects the data, and draws the conclusions. It is therefore evident that whilst seeking to recognise the experiences of people with learning disabilities, the 'traditional' qualitative research is still likely to encounter substantial barriers between the dominant researcher and the researched (Nind, 2008); and further argued that although measures might be adopted to minimize these barriers, its fundamental assumptions are flawed. This has been challenged by advocates for a 'new paradigm' of research with its origins in sociology (Kiernan, 1999). Kiernan forwarded that research should be viewed as a 'cooperative experiential enquiry' in which participants are seen as 'co-researchers' who generate the focus of the study (Kiernan, 1999). Also, Knox and colleagues emphasise collaborative research in which people with learning disabilities are viewed as research partners who play vital roles in maximising their involvement in the research process (Knox et al., 2000). This ensures that the research is conducted *with* the people rather than *on* the people (Knox et al., 2000). In this view, it is argued that the researchers adopt the epistemological assumption which sees people with learning disabilities as 'experts' and the researcher as someone who learns from the expert rather than testing his or her hypotheses on the passive research participants (Knox et al., 2000).

Overall, it is claimed that the involvement of people with learning disabilities as potentially active contributors is largely attributable to the ideas of 'normalisation' in the 1960s and 1970s (Walmsley, 2001), reinforced by the ideas of the social model of disability (Oliver, 1992) and had been influenced by the requirements for qualitative research methods (Walmsley, 2001). Qualitative research, it is argued, can access the perspectives and experiences of the oppressed groups lacking the power to make their voices heard through quantitative

academic discourse (Nind, 2008). However, it is argued that these 'normalisation' ideas were developed by non-disabled academics and professionals without the involvement of people with learning disabilities (Kiernan, 1999; Walmsley, 2001), an aspect that has been criticised as being uninformed. The voices of people with learning disabilities were almost completely silent and any changes that could come about were through non-disabled advocates (Walmsley, 2001).

Even within this 'new paradigm of research', there are still unresolved issues regarding who should own and direct research involving people with learning disabilities (Nind, 2008). In participatory research there is a commitment for the researcher to work alongside people with learning disabilities as allies (Chappell, 2000), whilst in emancipatory research (Oliver, 1992) it is argued that the stakes are higher where people with learning disabilities take control of the research (agenda) and the researcher acts as a facilitator (Walmsley, 2004a). However, Kiernan commented that the differences between 'participatory' and 'emancipatory' research are a matter of emphasis (Kiernan, 1999).

In this study, the researcher is not adopting either of the two approaches. The emphasis is on service users' and carers' views and experiences as the main focus of the study. Therefore ethical assessment of the study was not based on either of these paradigms. However, the researcher endeavours to operate in the spirit of the participatory paradigm where the views and experiences of people with learning disabilities are essential to addressing the objectives of this study. In this case, the views and perspectives of individuals with learning disabilities regarding communication with their carers and health and social care professionals will be sought which may influence clinical practice and public policy development.

It is argued that changes in social positions of disabilities have led to situations where research and evaluation are increasingly required to include the views and perspectives of people with learning disabilities

(Gilbert, 2004). A growing body of knowledge exists that embraces the view point of people with learning disabilities as crucial in judging the quality of the research (Booth and Booth, 1994, 2003; Goodley, 1996). For example, Booth and Booth, 2003 utilizes photovoice as a technique that challenges the established politics of representation by putting people in charge of how they document their own lives. As mentioned earlier, these developments reflect legal documents that emphasised consumer involvement in health services delivery and have added further impetus to involving people with learning disabilities in research. Notably, following introduction of the NHS Community Care Act, the Department of Health has begun to ask for service user views in research (Kiernan, 1999). Other influences include advocacy groups for example *People First* with the slogan: *Nothing about us without us*. In addition, research funding bodies such as the UK-based Joseph Rowntree Foundation and The National Lottery Charity Board Health and Social Research Initiative require applicants to demonstrate that their proposals contain strategies to actively involve people with learning disabilities (Kiernan, 1999; Walmsley, 2001).

One of the reasons for the limited involvement of people with learning disabilities in research may be related to cognitive impairments and communication difficulties. However, there is limited research on communication studies that investigate the communication needs of people with learning disabilities. For example it is argued that the research language may be difficult for service users to understand. Certain words may connote different ideas for people with learning disabilities (Braye, 2000 in: Walmsley, 2004b). Also, people with severe communication impairment may be heavily dependent on carers for their communication needs. Whilst it is perfectly reasonable to include carers views, their views may not represent service users (Kiernan, 1999). Even the views of people with mild learning disabilities may not be representative of those with severe communication impairments (Kiernan, 1999). This again reflects the

need for accessible communication to enable people to participate meaningfully in research studies. For example to be able to manage the research agenda, frame a research question; disseminate research findings; effective communication is at the heart of it all. Although agreement regarding 'accessible information' remains lacking, it is argued that good practice guidelines exist (Walmsley, 2001). Specific techniques have been developed to design questions and also to overcome the tendency of people with learning disabilities to 'acquiesce' during interviews (Kiernan, 1999). One of these techniques for example is the use of simplified language plus illustrations (Walmsley, 2001). In this study, whilst the focus is on communication, the approach and the research design is tailored to enable accessible communication between the researcher and the participants.

With regard to 'inclusion,' it is argued that a number of researchers have failed to investigate what skills people with learning disabilities have and what extra supports they may need to enable them to communicate and to become effective in their research involvement (Walmsley, 2001). The identification of the communication needs of the individuals will facilitate inclusion in the research processes and may ensure that the voice of the service users is represented rather than that of researchers and health and social care professionals. It is only by understanding peoples' views regarding communication that steps may be taken to remediate any communication difficulties and ensure that the study reflects the views and experiences of the learning disabilities population. In conclusion, communication is a fundamental requirement of any inclusive research. Researchers and politicians may be over ambitious and have exaggerated expectations regarding service user involvements in research; rather more attention should be devoted to communication because it prepares the ground for any meaningful inclusive research.



## 3.3 The study methodology

### *3.3.1 Introduction*

This section will further demonstrate the choice of qualitative research methodology adopted and the philosophical underpinning utilized in this study. The section will also provide the rationale for the design and methods used in this study.

As discussed in the section above, the relative merits of quantitative and qualitative paradigms have long been debated (Patton, 1990). Qualitative research uses a naturalistic approach that seeks to understand phenomena in a context-specific setting whilst the positivist or quantitative research uses experimental methods and quantitative measures to test hypothetical generalisation (Hoepfl, 1997). Each of these paradigms is fundamentally different and leads to different kinds of knowledge. Qualitative approaches are especially recommended for research involving people with learning disabilities as discussed earlier. Whereas quantitative researchers seek causal determination, prediction and generalization of findings, qualitative researchers instead, seek illumination, understanding and extrapolation to similar situations (Hoepfl, 1997). Furthermore, proponents of qualitative research claim that quantitative study is not able to take full account of the multiple interaction effects that take place in a social setting (Cronbach, 1975). Thus, it is time to 'exorcise the null hypothesis' because it ignores effects that may be important but not statistically significant (Cronbach, 1975). It is argued that there are so many ways our understanding of the world can be represented (Eisner, 1991). Qualitative inquiry accepts the complex and dynamic nature of the social world (Hoepfl, 1997). Whilst no claim is made regarding any superiority of qualitative over quantitative research however, consideration of the focus of this study and the participants involved, as the primary data source, indicates congruence with the tenets of qualitative investigation.

Moreover, other researchers commented that it is irrelevant to engage in paradigms and methodological debates because each has its role and serves a different purpose (Patton, 1990, 2002). Therefore, a 'paradigm of choice' which seeks methodological appropriateness as the primary criteria for judging methodological quality is advocated (Patton, 2002). 'Paradigm of choice' recognises that different methods are appropriate for different situations (Patton, 1990). It enables situational responsiveness: that is, designing a study that is appropriate for the specific inquiry situations (Patton, 1990). Meanwhile, other researchers argued that both qualitative and quantitative methods can be effectively utilised in the same research project and may lead to findings that neither type of analysis could provide alone (Patton, 1990; Strauss and Corbin, 1990). However, this study will utilize only the qualitative approach as the methodology of choice because it seeks to understand context-specific phenomena and it will enable the study objectives to be realised.

Furthermore, it has been forwarded that the goal of health services research should be to produce knowledge in which we can be reasonably confident and to produce findings that are relevant to policy makers and practitioners (Murphy et al., 1998). Therefore, the decision about whether qualitative, quantitative, or both methodologies should be based on which approach is likely to meet the research objectives most effectively and efficiently (Murphy et al., 1998). The essence of this study is to understand the views and experiences of community-based adults with learning disabilities regarding communication with their carers and health and social care professionals for example doctors and nurses. It seeks to investigate how people with learning disabilities and epilepsy communicate with their carers and health and social care professionals regarding epilepsy and related issues such as seizures, medication and quality of life. It also seeks to solicit carers' views and perceptions regarding their communications with service users and health and social care professionals. This focus of the project lends itself to a qualitative

approach which is characterised by a focus on participants' meaning attached to behaviour (Patton, 1990). As participants who live in the community, qualitative research uses the environment (natural setting) as a source of data (Eisner, 1991; Lincoln and Guba, 1985; Patton, 1990). Qualitative research seeks, to study social interactions and understand service users' and carers' perspectives regarding communication, provide insight into what their views and experiences are, and why they do what they do (Rowan and Huston, 1997). It takes into account the multiple views as expressed by people with learning disabilities and their carers regarding communications with health and social care professionals (Lincoln and Guba, 1985).

Also, the literature review reveals a paucity of research on communication regarding people with learning disabilities with epilepsy, in particular the service users' views regarding communication. Qualitative methods are particularly useful at the exploratory stages of research where they will often pave the way, or even set the research question, for later research which could either be quantitative or qualitative in nature (Murphy et al., 1998; Patton, 1990). The findings that emerge from a qualitative study may also aid conceptualization or may support the generation of hypotheses for future research (Glaser and Strauss, 1967; Murphy et al., 1998). The target audience for this study includes: service users, health and social care professionals and policy makers. Qualitative studies are particularly useful in providing descriptive information and understanding of the context in which policies will be made and implemented (Murphy et al., 1998).

### *3.3.2 Philosophical underpinning utilized in this study*

The above commentary has demonstrated why qualitative approach is the paradigm of choice for this study. Numerous forms of the qualitative approach exist. The most common ones include; Grounded theory; Ethnography; Phenomenological and Case study methodologies. However, in order to meet the stated project aim and

objectives of this study as outlined in Chapter 1, the paradigm of naturalistic inquiry forwarded by Lincoln and Guba, (1985) was considered the most appropriate for this study.

Overall, the naturalistic inquiry paradigm is underpinned by two key assumptions. Firstly, people cannot be separated or removed from their natural environment physically, socially or culturally. Humans constantly seek to influence their environment and are in turn influenced by it; behaviour can be explained in terms of the interaction between individuals and the environment. Secondly, it is not possible to observe the personal meanings and perspectives that guide human behaviour within a given environment. There is always an interpretive element between people and their environment. This means that each person might behave differently in a given set of circumstances (Lincoln and Guba, 1985) and unique experiences and knowledge are brought to the situation (Lincoln and Guba, 1985).

This study involves community-based adults who live and interact with their natural setting and it may not be possible or it may be inappropriate to detach their constructions of realities and meanings from the environment in which they are derived. It is argued further that since context is heavily implicated in meaning, naturalistic inquiry is carried out in natural setting (Lincoln and Guba, 1985); and that the contextual nature of the setting requires a human instrument (the researcher). This is because the 'human' is more adaptable and can accommodate any emerging or changing circumstances. This emphasis on the adaptable nature of the researcher makes this paradigm particularly suitable for studies involving people with learning disabilities and epilepsy who may be cognitively impaired and also may have communication difficulties.

Contrary to the positivist view, naturalists hold the axioms that: 1. realities are multiple, constructed and holistic; 2. the knower and the known are interactive and inseparable; 3. only context-bound

hypotheses are possible; 4. inquiry is value-bound (Lincoln and Guba, 1985).

### *3.3.3 Rationale for this design*

Firstly, realities are multiple, constructed and holistic. The aim of such a study is to seek information, views and experiences of the individuals being studied. The views of carers and health and social care professionals regarding communication may differ from service users. Even among the individual service users, their views of communication and their experiences of epilepsy may differ significantly. The approach in this study would be to invite holism when accessing the individuals' views and experiences of communication regarding epilepsy and related issues. This focus of the study is in contrast with the positivists' views who argue that realities are single and objective (Lincoln and Guba, 1985).

Secondly, the knower and known are interactive and inseparable (Lincoln and Guba, 1985). This study sought to investigate service users and carers' subjective views and experiences regarding communication and epilepsy related issues. Any attempts to see knowledge as objective, separate and independent as claimed by the positivists would be unhelpful to the aim and objectives of the study.

Thirdly, only context-bound hypotheses are possible (Lincoln and Guba, 1985). People's views and experiences are linked to the context in which they are experienced. It is claimed that habits and behaviours are often congruent with their social and cultural milieu (Rowan and Huston, 1997). When accessing people's views and perceptions it is necessary to share their views of the world in which they live, their experiences and beliefs are often linked to the context in which the phenomena are experienced. However, an experience is what the person tells you, it may be irrelevant to prove or disprove that but they can share their views of the world in the context in which they are experienced. These subjective and multiple views may

lead to a new insight that may be useful for the development of concepts or hypothesis. This approach contrasts clearly with the positivists who seek objective and generalisable views. Also, the qualitative approach in this study was not predetermined, straight forward or linear but cyclical. It is argued that data collection and analysis occurs simultaneously as they reinforce one another (Miles and Huberman, 1994). This is also congruent with the emergent design of the study and any attempts to control variables may be impossible.

As mentioned earlier, semi-structured interviews using an interview schedule would be employed to keep the interview focus on key elements. People with learning disabilities may have some communication difficulties as well as cognitive impairments. Therefore, some prompts would be inserted into the interview schedule and supplemented with photographs and Boardmaker signs and symbols to elicit responses (Mayer-Johnson, 1992).

Diaries are widely regarded as useful tools for collecting data especially when used after face-face interviews (Jacelon, 2005). It is argued that a combination of interviews and diaries can be used to approximate observation (Jacelon, 2005). Furthermore, participants are community-based individuals and the challenges inherent with observation in such environments are significant. In particular, home observations are intrusive and highly invasive. Besides, there is no guarantee that observation will automatically yield credible findings; in particular, considering the 'Hawthorn effect'. Instead, an alternative would be carer communication diaries.

Although diaries have been applied in research studies to gather data, they are less used in comparison with other data collection methods for example, in-depth interviews and participant observation (Clayton and Thorne, 2000). However, carer communication diaries when used together with interview may yield very rich data. Health care

professionals and service users may use solicited diaries to reflect both on practice and in practice and this may illuminate findings that neither interviews nor participant observations alone can provide.

Communication is an interpersonal skill; we may not be aware of our own communication let alone others; often no attention is given to how we communicate and how we receive or provide feedback. When participants are given the opportunity to take stock of their own communication it may lead to a positive learning curve. Moreover, it is argued that the fusion of the 'emic' (inside) and 'etic' (outside) perspectives is the hallmark of qualitative research (Clayton and Thorne, 2000). This will provide carers with the opportunity to document their experiences, perceptions and views and feelings about communication and epilepsy related issues during or immediately after the event/activity by providing a vivid account of the 'emic' perspective (Clayton and Thorne, 2000). However, communication and therefore reflections do not occur in a vacuum but are contextual in nature. To enable the exploration of communication, it was considered that a daily or routine activity rich in communication may facilitate reflection.

In furtherance to the above axioms, Lincoln and Guba forwarded some operational characteristics as key elements for consideration when undertaking a naturalistic study: 1. Natural setting, 2. Identification of an human being as the main data collection tool 3.The utilization of tacit knowledge, 4. Qualitative interviews, 5. Adoption of purposive sampling, 6. Emergent design, 7. Inductive data analysis, 8. Idiographic interpretation, 9. Tentative application, 10. Focus determined boundaries, 11. Special criteria for trustworthiness, 12. Negotiated outcome and 13. Adoption of case study reporting mode.

### *3.3.4 Implications of the naturalistic inquiry paradigm*

1) *Natural setting*: Participants are community based residents and it is important not to dissociate any meanings they attach to their experiences from the environment in which they live. Naturalists believe that people cannot be separated from the physical, social and cultural elements of the environment and that behaviour is influenced by environmental interactions.

2) *Identification of an human being* (researcher) as the main data collection instrument: The researcher and researched are seen to be interactive and influence each other. There is the need therefore for adaptability on the part of the researcher depending on emerging circumstances. The researcher is the primary data collection tool, as it is only humans who can be adequately honed and adapt to the changing needs of individuals. This human adaptability is particularly useful in studies that involve people with learning disabilities and epilepsy who may have communication difficulties.

3) *Utilization of tacit Knowledge*: The researcher makes use of tacit (intuitive, felt knowledge) in addition to propositional knowledge (i.e. knowledge expressed in language form). It is argued that the nuances of the multiple realities is best appreciated in this way; also much of the interaction between the researcher and the participant occurs at this level (Lincoln and Guba, 1985). In particular, people with learning disabilities may employ non-verbal forms of communication and the interactions between the researcher and the participants will necessitate the use of intuition as well as expressed knowledge in language form. The researcher must acquaint himself thoroughly with the context in which the phenomenon is experienced and thus facilitate the use of intuitions. It is argued that certain elements have to be experienced to be understood (Lincoln and Guba, 1985). In the current context, following familiarization processes, the researcher builds on his knowledge and uses intuitions to enable understanding of the participants' views regarding communication and their



experiences of epilepsy and related issues. In particular, the communication of emotion may be best expressed in non-verbal form, and this is dependent on the researcher's skilled observations, knowledge and interpretations to understand participants' experiences and feelings.

4) *Qualitative Interviews*: The popularity of interviews as the main research data in health services is based on the assumption that there are always reasons why people behave in certain ways. It is claimed that people do not merely respond to stimuli but act on the basis of their interpretation of the world around them and their experiences within it (Murphy et al., 1998). It is not possible to interpret behaviour simply by means of observation because it is not possible to understand the personal meanings and views that guide people's behaviour within a given environment (Patton, 2002). Also, it is argued that if you want to understand what people do, believe and think, then ask them (Murphy et al., 1998). Regarding the paucity of studies in this field, interviews are particularly suitable for this exploratory type of research (Murphy et al., 1998). Service users and carers' interviews constituted the main data for this study. Interviews enabled the individuals to tell their stories, perceptions and experiences regarding communication and epilepsy related issues in the way they experienced it thus, allowing the multiple realities to be elicited.

5) *Adoption of purposive sampling*: Recruitment and sampling is purposive rather than random or by probability means. The aim is to gain an in-depth understanding of communication between people with learning disabilities and epilepsy and their carers (Patton, 2002). Therefore information-rich cases as outlined in the inclusion criteria would be sampled (Patton, 2002); in this case only people with learning disabilities and epilepsy and their carers within a particular locality in Scotland was sampled.

6) *Emergent design*: Research design is emergent (unfolding) rather than predetermined as argued by the positivists because it is impossible to make predictions due to the multiple realities. There is the need to maintain openness and be adaptable to pursue new paths of discovery (Patton, 2002). Ongoing analysis of the data was used to inform the questions to be asked in subsequent interviews and also preliminary findings will inform the need and nature of the carer communication diaries compared with observational methods.

7) *Inductive data analysis*: Naturalists prefer inductive to deductive data analysis; inductive analysis is more likely to identify the multiple realities to be found in the data. In this study interviews and diaries would be analysed through the identification of themes that emerge. This may also facilitate the development and the conceptualisation of theories.

8) *Idiographic application*: Data is interpreted idiographically (in terms of the particulars of case) rather than nomothetically (generalization). In this study data will be interpreted based on the individual interviews or cases. This allows the multiple voices, realities and views to be accommodated.

9) *Tentative application*: Findings are applied tentatively instead of making generalisations of the findings because the multiple realities are different. The findings to some extent are dependent upon the particular interactions between the researcher and the participants that may not be transferable in a different setting. Interpretation of the analysis may lead to understanding of the nature of communication between service users and health and social care professionals.

10) *Focus determined boundaries*: Boundaries are mapped out based on the emergent design of the study. Critical review and appraisal of the literature and discussions with colleagues and project

collaboration team informed the inclusion and exclusion criteria adopted in this study.

*11) Special criteria for trustworthiness:* The conventional trustworthiness criteria (internal and external validity, reliability and objectivity) are incongruent with the axioms of naturalistic inquiry. However, in this study, the proposed criteria: credibility, transferability, dependability and confirmability which address the trustworthiness of naturalistic inquiry are applied in the collection and the analysis of the data.

*12) Negotiated outcome:* All participants are community-based individuals who live in their own homes. The places and times for the interviews are negotiated with participants.

*13) Case study reporting mode:* The preference of a case study reporting mode is advocated over any statistical or technical means because it is more adapted to a description of the multiple realities encountered at a given setting. Findings are reported to reflect the individuals' with mild learning disabilities and their carers' perspectives of communication with health and social care professionals regarding epilepsy and related issues.

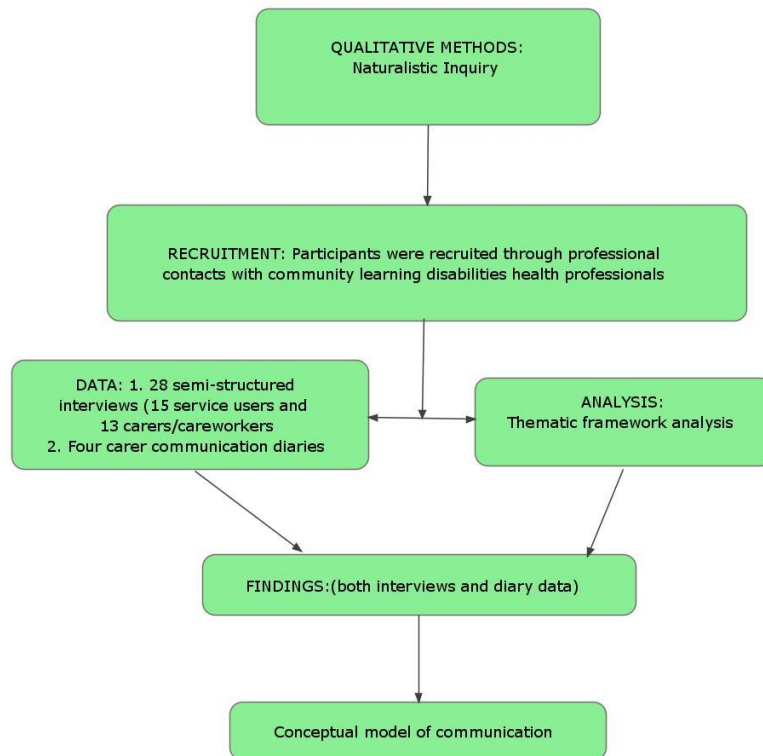
### *3.4 The design*

This section demonstrates how the naturalistic inquiry paradigm described above was utilized to design the study. The section will cover the following key areas:

- Flow chart of the design
- The study setting
- Recruitment of participants
- Sampling
- Ethical considerations
- Informed consent
- Data collection
- Logbook/field journals
- Sample size
- Gaining entry
- Summary of the application of the key characteristics of the naturalistic inquiry paradigm to this study
- Reflection of the interviewing process
- Criteria for assessing the trustworthiness of the study
- Table of criteria for trustworthiness
- Summary of strategies used to establish the trustworthiness of the study.

The overall design of the study is shown in the flow chart in Figure I below.

**Figure I. Flow chart of the study design**



### *3.4.1 The study setting*

This project is a community-based study within a particular locality in Scotland with a population of about 223,850 (2004 census) of whom 5632 are known to have learning disabilities. As mentioned in the literature review, the population of people with learning disabilities in our communities has increased tremendously following the advent of de-institutionalisation and the closure of long-stay hospitals. The study locality is a rural community in Scotland, which has seen the closure of a long-stay hospital. The majority of its patients, in particular those with mild learning disabilities, have been resettled in communities and are either living independently or supported by carers.

The essence of a collaborative approach is emphasised in the successful conduct of this study. The study was conducted in collaboration with the appropriate Managed Clinical Network for

Epilepsy comprising Neurology consultants, GPs, epilepsy specialist nurses, community learning disability nurses and epilepsy field workers.

### *3.4.2 Recruitment*

Thirty participants (service users and their carers) were recruited through community learning disability teams within the study locality. The project was introduced to potential participants by their health and social care professionals who had written information regarding the study (see Appendix 1) and had opportunity to discuss the requirements at length with the researcher. Participants were then nominated based on the assumptions that: 1. The person fits the inclusion criteria for the study as described below. 2. The person may be willing to participate and 3. The person has given a provisional consent to participate. Following this, personal contacts were made with the participants by the researcher through the health and social care professionals and consent sought for the study.

It is important to note that due to the pragmatic nature of this study recruitment would have been impossible without collaboration with health and social care professionals as accurate diagnosis of epilepsy is dependent on clinicians. Although this was recognised as a possible limitation, steps were taken to reduce biases. There was no guarantee that participants nominated by health and social care professionals would automatically participate.

### *3.4.3 Sampling strategies*

In the sampling process, the following inclusion and exclusion criteria were applied by the health and social care professionals who are members of the local Managed Clinical Network for epilepsy (MCN).

#### *Inclusion criteria*

- Community-based adults' age 16-50 years and either receiving or eligible for learning disabilities services. The upper age limit

of 50 was decided because dementia is reported to set in earlier in people with Down syndrome estimated at 50 years. (See literature review chapter 2).

- The service user is taking antiepileptic medication to control seizures.
- The service user has mild learning disabilities and can communicate through conventional means.
- Carers have cared for the service user for at least 12 months and have taken part in decision-making regarding the service user with health and social care professionals.
- As per ethical protocol, only participants capable of giving informed consent were included.

*All the above inclusion criteria were applied.*

#### *Exclusion criteria*

- People whose learning disabilities relate to post-birth brain damage for example through accident
- People with concomitant learning disabilities and autistic spectrum disorders.
- The individual has an established non-epileptic seizure disorder
- The person is unable to communicate through English language.
- People with moderate to severe disability were also excluded. The severities of the disabilities were determined by the health professionals. It is unclear which criteria were used. However, it is claimed that the medical versus social model dichotomy are not mutually exclusive, rather they provide a reciprocal cultural enrichment and cross fertilization of ideas. Actions between medics and other professionals are encouraged in order to optimize healthcare for people with learning disabilities (Lopez-Rangel et al, 2008).

*Carer communication diaries:* Carers were conveniently sampled to keep communication diaries for a period of two weeks. The inclusion and exclusion criteria reflect those of the interviews as described

above. In addition, only carers with good literacy skills who can speak and write in the English language and have been interviewed for the purpose of this study were sampled.

## 3.5 Ethical consideration

### *3.5.1 Introduction*

Ethical issues regarding the involvement of people with learning disabilities have been discussed earlier (see sections on paradigms and methodologies). This project was scrutinised and approved by the local Research Ethics Committee. Particular concerns raised include: informed consent, interviewing 'vulnerable' people in their own homes, anonymity, tape-recording. These were all dealt with through the methods of recruitment and data collection processes.

### *3.5.2 Informed consent*

It is claimed that obtaining informed consent to participate in a research study presents particular ethical challenges involving people with learning disabilities (Cameron and Murphy, 2007; Freedman and Freedman, 2001). It is argued that three key elements must be satisfied before an individual consent may be considered informed: (1) the person receives detailed information regarding the project (2) the person is capable of making a decision regarding his or her participation in the project and (3) the decision is made autonomously or voluntarily without coercion or duress (Dye et al., 2004; Nind, 2008; Stalker, 1998). It is claimed that people with learning disabilities recruited as research participants will be deemed vulnerable if their capacity to provide informed consent is compromised (Roberts, 1999). Furthermore, it is asserted that information alone is not an adequate predicate to meaningful choice (Grisso & Appelbaumin, 1998; Cameron and Murphy, 2007), there is the need to include sufficient information in a suitable format for people with learning disabilities. Specific challenges in seeking consent involving people with learning disabilities may relate to



cognitive impairment, communication impairments and the limited opportunities to exercise choice (Cameron and Murphy, 2007; Freedman and Freedman, 2001; Nind, 2008). However, peoples' capacity to consent was found to improve when the decision-making task was progressively simplified by providing information as separate elements and modifying the assessment of capacity to ensure that response is less dependent on expressive verbal ability (Wong et al., 2000). Nevertheless, it is claimed that every project is different and so the consent processes will also differ. It is asserted that in order to identify any such vulnerability, the informed consent must be made on individual basis (Iacono and Murray, 2003). Below are the consent protocols for this study.

### *3.5.3 Consent for service users*

- Information regarding the project (Appendix 2) was sent to all potential participants with mild learning disabilities through professional contacts (member of the learning disabilities team). Information was presented in an appropriate format for people with learning disabilities, including the use of simplified language backed up with illustrations.
- The project was explained to the participant by a member of the learning disabilities team, carer or a member of day-centre staff. If the participant expressed an interest then a meeting was arranged between the researcher and the person with learning disabilities, together with the health and social care professional nominating them. The project was explained further verbally, supported with illustrations to promote understanding.
- Following this if the individual was satisfied and willing to participate at that instance, the date and time were negotiated for the interviews. Detailed information and the consent forms were sent to participants through professional contacts at least 48 hours before the date of the interview.

- At the start of the interview the project was explained further and the researcher answer any queries, and also, ensured that the participant was still willing to participate voluntarily. It was essential to establish that the participants' circumstances had not changed since the last meeting. If there were no further queries regarding the information the consent forms (Appendix 3) were then signed and counter-signed by the researcher in the presence of either the nominator or the person's carer. The participant could also have a supporter present during the consent process or at the interview if they so wished.
- Two consent forms were signed by each participant, one was retained by the participant and the other kept by the researcher. The interview session then proceeded immediately.
- The validity of the informed consent was taken into consideration by reference to the following: (1) the participant's knowledge and understanding of the project (2) the person's ability to weigh and decide their willingness to participate and (3) Service users were asked to nominate a witness and if present, agree that the consent was valid (Young and Chesson, 2006). A specific consent was obtained for the audio-recording of the interviews.

#### *3.5.4 Consent for carers*

- In broad terms, the consent process for the carers followed that of the people with learning disabilities.
- Written and detailed information explaining the project was sent separately to all potential participants through professional contact for example, a learning disabilities team member, or the day centre manager (Appendix 4).
- Follow up contacts were made with those who expressed interest in participating. The study was explained further and all queries relating to the project clarified. If the participant wishes to continue, an interview date was negotiated in the future.

- At the start of the interview, participants were briefed again and the researcher answered any queries and also ensured that the participant's circumstances had not changed since the last meeting. If the participant was satisfied and still keen to participate, the consent forms (see Appendix 5) were given for the individual to append his/her signature and this was countersigned by the researcher.
- A copy was retained by the participant and one kept by the researcher. Specific consent was obtained for the audio-recording of the interviews.
- In both cases (service users and carers), assurance of confidentiality and anonymity were given both verbally and in writing.

#### *3.5.5 Consent for the communication diaries*

Carers were invited to participate following each interview. Participants who expressed interest in keeping the diaries were noted. They were contacted at a later date with detailed information regarding the diaries (Appendix 6). After a few days, personal (one-on-one) contacts were made by the researcher. The contents of the diary were explained further to the participants; the researcher answered any queries they may have and also showed them how the entries should be made. If participants were satisfied with the information and were still willing to participate, the consent forms were signed and counter-signed by the researcher.

A copy of the consent forms was each kept by the participant and the researcher. Telephone contacts were maintained with all participants throughout the two weeks period. This eliminated any difficulties faced by participants regarding the diaries. In all cases, all the signed consent forms were securely stored away from unauthorised persons in the university.

### 3.6. Data collection

As mentioned above, data for this study were collected from two main sources:

*1. Semi-structured interviews and 2. Carer communication diaries*

*1. Semi-structured interviews:* Interviewing is a conversation with a purpose (Dexter, 1970 in: Lincoln, 1985). It is argued that the word 'unstructured' is a misleading term because it is impossible to imagine an interview which is totally without structure (Murphy et al., 1998). Semi-structured interviews using an interview schedule were considered most suitable for interviewing people with learning disabilities as it allowed the interview to be focused on key issues. The schedules were designed to ensure that the same information was asked of each participant (Appendices 7 and 8). There were no predetermined responses, and the researcher was allowed to probe for further information (Hoepfl, 1997; Lofland and Lofland, 1984). Relevant prompts were inserted into the interview schedule to ensure that participants understand the questions better and also help eliminate ambiguities in the questions as much as possible. Service users and carers were interviewed to enable the individuals to tell their experiences, perceptions and views regarding communication in the way they experienced it.

As mentioned earlier, the use of signs and photographs to elicit responses have been widely associated with qualitative studies (Creswell, 2007) and may be more useful for people with learning disabilities who have communication impairments (Cameron and Murphy, 2007; Young and Chesson, 2006). It is claimed that the researcher has to establish the best medium through which communication takes place and also conceptualises that it is meaningful to the service user (Lewis and Porter, 2004). It may not be sufficient to use verbal language or offer different modes of communication but supplementary materials may be required including the use of pictures, cue cards and Talking Mats (Lewis and

Porter, 2004). Following consultations with the MCN, in particular the community learning disability nurses and the speech and language therapists, suitable Boardmaker signs and photographs (Mayer-Johnson, 1992) were selected and were used to supplement the interview schedule. However, it was discovered that the Boardmaker signs were not consistent in terms of what they denote or represent. Therefore, the choice of which Boardmaker signs should be used to support the interviews was guided by pre-pilot responses from service users. Samples were taken to a day-care centre to solicit service users' views regarding which signs were more representative and more recognisable. This proved valuable and informed the selection of Boardmaker signs that were used. Over all, the Boardmaker signs enabled the interviews to be focused on key elements for example on communication and epilepsy related issues such as medication, listening and talking, which allowed the responses to be elicited spontaneously.

2. *Carer communication diaries*: Semi-structured diaries were developed logged with sufficient space for free text entries. Carers were invited to choose one routine or daily activity/event from each of the three categories. For example, *routine planning* e.g. budgeting/finances, shopping; *domestic chore* e.g. cooking a meal, laundry or cleaning activity; and *health management* e.g. taking or the refusal of medication, healthy eating or exercise. All activities were given equal weighting in terms of context and content (Appendix 9). Diaries were kept for a duration of 7-14 days (Jacelon, 2005). Participants were advised to make entries during or immediately after each activity or event.

### 3.6.1 Pilot interviews

The interview schedule (topic guide), including the use of photographs and Boardmaker signs and symbols, were piloted with four participants within the neighbouring locality (two services users, one carer and one care-worker). Following this no significant changes

were made. However, service users reported they communicate mostly through verbal means with limited involvement of non-verbal forms of communication and may not need to use the Boardmaker signs and symbols. Therefore, it was decided that the researcher establish at the start of the interviews, the participants' preferred method of communication. If the participant was not familiar with the Boardmaker signs and symbols, it would be logical to exclude them, otherwise it could be more confusing rather than facilitating communication. However, the use of photographs for eliciting responses has been widely applied in the general population (Houts, 2006) and may be particularly useful for interviewing people with learning disabilities who may have some form of cognitive impairment or limited recall and communication difficulties. These were maintained and used throughout the interviewing process with all participants.

*Pilot diary:* A sample diary was piloted within the neighbouring locality. Following this it was evident that carers may have different roles and responsibilities with their service users. For example, the role of a carer at a day-care centre may differ from a home caring role. Therefore, it was necessary to include a summary of the role(s) of carers.

*Log book/Field journal:* Through out the study, a log book was kept by the researcher. This contains entries of the project progress. For example, it contains relevant information from the literature review, meetings, conferences and colleagues' discussions. It served as a reference book and also, was used to facilitate communication in particular, for the sharing of information with supervisors and members of the project collaboration team. It also served as an important document for any purposes of auditing the study. Similarly, a field journal was kept containing summary notes in particular, observational and reflexive notes during and after interviews. These were all stored away in a secured place to maintain confidentiality.

### *3.6.2 Sample size*

Initially, fifty participants (25 service users and 25 carers) were envisaged for this study. However, data were collected from 28 participants. One carer declined to participate and another carer did not meet the inclusion criteria. Thus, 13 pairs and two additional service users were included in the sample. Within that five carers were anticipated to keep the communication diaries. In qualitative studies there are no strict guidelines or rules regarding when to stop data collection (Hoepfl, 1997; Patton, 2002). Some qualitative researchers argue that data collection and analysis normally continue until: 1. Exhaustion of resources (Hoepfl, 1997) 2. 'Saturation' of data for example, when the same themes and issues recur continually (Gibbs, 2002). 3. When there is emergence of regularities (Hoepfl, 1997) 4. When the researcher feels confident that the descriptions fit the phenomenon under study (Van Manen, 1990) and 5. When the researcher feels there is overextension, or the work is going too far beyond the confines of the study (Lincoln and Guba, 1985).

Patton commented that the validity, meaningfulness and insight generated from qualitative inquiry has more to do with the richness of the data, and the analytical abilities of the researcher rather than the sample size (Patton, 2002). Patton also commented on the trade-off between breadth and depth in which a specific experience may be studied over a large number of people or an in-depth study of an experience over a smaller number of people (Patton, 2002). Nevertheless, it is argued that it is data 'saturation' that matters the most rather than sheer numerical size of the 'sample'. Sampling is aimed at insight about the phenomenon rather than on empirical generalization (Patton, 2002). In this study, saturation was achieved following the analysis of 28 participants interviews (15 service users and 13 carers) by taking into account the objectives of the research study and the need to achieve in-depth description (Hoepfl, 1997).

Data saturation in this study was determined as follows: Each set of interviews were transcribed verbatim as soon as they were collected. The researcher familiarized himself with the data by reading through the transcript over and over and taking notes of emerging themes. New phenomena or deviant cases that emerged or were not fully covered were identified and followed up in the next set of interviews for clarification. This process was continued until the establishment of 'regularity'. That is, when no more new insights emerged after the same questions were asked. The points of saturation are thus dependent on the insights, experiences and new phenomena that emerged during the interviews. This informed the need for further exploration in subsequent interviews. Therefore, saturation points were differently reached for service users and carers.

### *3.6.3 Gaining entry or access*

Access to people who live in the community in particular, to participate in research can be extremely difficult. It may involve both professional and ethical implications as well as logistical constraints. However, it has long been recognised that building and maintaining trust is an important task for the researcher (Lincoln and Guba, 1985) and that the task of contacting individuals at the inquiry site has both formal and informal aspects (Lincoln and Guba, 1985). Naturalists believe that the best way to gaining successful access to a situation is to develop contacts in order to eliminate barriers (Lofland and Lofland, 1984). Furthermore, it is documented that health and social care professionals at the site of the research can have considerable influence in terms of facilitating access (Stalker, 1998) and thus the development of a collaborative relationship with the MCN was vitally important to this study.

The researcher developed and maintained good working relationships with the health and social care professionals of the study since the commencement of this project. Contacts were maintained through email, telephone discussion and more importantly through numerous



face-face contacts to promote familiarity with the study setting. A number of field visits were made to facilitate discussion with professionals regarding recruitment and also to interact with potential participants to facilitate familiarization with the learning disabilities population. This approach was rewarded during the data collection stages. In particular, the community learning disability team in the recruitment locality who acted as 'gate keepers' provided enormous support for this project. They were particularly helpful by (1) informing and nominating potential participants (2) playing an advisory role in the recruitment stages and more importantly by introducing potential participants to the project. As a result, recruitment which could otherwise have proved challenging was very much facilitated. Overall, this collaborative relationship has not only facilitated participant recruitment but promoted the researcher's familiarity with the study population in particular, the development and maintaining of trusting relationships with participants. This allowed the fusion of the individual horizons and expectations which prepared the grounds for data collection. Corsaro referred to this as "prior ethnography" (Corsaro in: Lincoln and Guba, 1985), and argued that it provides the baseline for cultural accommodation and informal orientation that would enhance the efficiency and effectiveness of the formal work (Lincoln and Guba, 1985). It also offers participants the opportunity to interact with the researcher. In addition, it facilitates the building of rapport (Cameron and Murphy, 2007). This period of familiarisation also enhanced the researcher's communication skills with the learning disabilities population overall leading to a more credible data (Lincoln and Guba, 1985).

Summary of how the naturalistic paradigm is applied in this project is shown in Table 2 below.

**Table 2. Summary of the application of the key characteristics of the naturalistic paradigm in this study**

| Characteristic                       | Application in this study   |
|--------------------------------------|---|
| Natural setting                      | Community-based participants. Data were collected mostly in participants own homes  |
| Human instrument                     | The researcher was the primary data collector   |
| Utilization of tacit knowledge       | Knowledge derived from intuition, personal experience and knowledge merged from the study   |
| Qualitative methods                  | Semi-structured interviews, semi-structured diaries and researcher field notes were used to collect data                                |
| Purposive sampling                   | Participants were purposefully sampled for interview  |
| Inductive analysis                   | Emergent themes and findings were derived from the data   |
| Emergent design                      | Analysis of the interview data informed the structure of the carer communication diary  |
| Negotiated outcome                   | Participants' participation was negotiated through the consent process. Dates and interview locations were negotiated with participants |
| Idiographic interpretation           | Data were recorded and processed on individual basis. This allowed the accommodation of the multiple realities                          |
| Tentative application                | Analysis led to the identification of communication method, limitations in communications, barriers to communication                    |
| Focus-determined boundaries          | Study was based in a particular locality with inclusion and exclusion criteria  |
| Special criteria for Trustworthiness | Credibility, dependability, confirmability and transferability are demonstrated   |

#### *3.6.4 Reflections of the interviewing process*

Interviewing can be both a challenging and an exciting experience. However, it is argued that the interviewer makes observations, takes decisions, asks questions and interprets responses (Patton, 2002) and as a result both the researcher and the researched are both potential sources of biases. Thus, the researcher's reflections of his decisions, encounters, interventions and interpretations are essential as they improve the credibility of the study. Interviewing people with learning disabilities may be more challenging and demands some form of preparation. Practice interviews were undertaken with staff with clinical experience. This enhanced the researcher's familiarization with

the interviewing tools for example the tape-recorder and the appropriate use of prompts, Board-maker signs and photographs during the main interviews. Whilst this appeared to work well, there were still significant issues observed during the interviewing stage. These were recorded in the researcher's Journal and are considered worth reflecting upon. This pertains particularly to the interviewing environment (participant's home). The 'context' where people developed their feelings, experiences and views regarding communication was a significant consideration in the design of this study.

The challenges of interviewing people in their own home have been reported in the literature (Herzog, 2005; Parkman, 1996). It is argued that the selection of interview places should not only be based on technical convenience and comfort but should have some social context connotations, because the environment plays a part in the construction of reality (Herzog, 2005). Some researchers are of the view that the principles for determining interview places and times should be based on equity (Seidman, 1991), claiming that the interviewer is the 'taker' and participant is the 'giver' and thus, the researcher must be willing to adapt himself to the preferences of the participants (Seidman, 1991). Whilst some researchers argue that sensitive and highly emotive issues are best conducted at home (Adler & Adler, 2002 in: Herzog, 2005), others are of the view that participants should be allowed to set the time and place suited for them (Warren, 2002 in: Herzog, 2005).

Participants were offered the choice of a place to be interviewed for example, at their own homes, day centres, the GP surgery or a suitable place in the university. The interview dates and times were then negotiated with participants. The majority of the participants, who consented, preferred to be interviewed at their own homes. All the interviews were normally preceded by a warm welcome often over a cup of tea. Prior familiarization through the recruitment stages led

to the introduction occurring more spontaneous and informally. I was introduced to the participant by the health and social care professional. A decision was made to always interview the service user first in order to alleviate anxiety. The interview process was explained again to participants including the assurance of confidentiality as specified by the consent process. Audio-taping was only done with the participant's consent. Two carers declined for their interviews to be taped as a reflection of their autonomy. All participants were made aware that they could stop the interviews at anytime, take a break or make a cup of tea at anytime. However, no participant opted for a break. The length of the interviews varied with a mean duration of about half an hour (30mins) for service users. Carers' interviews were comparatively longer at about 45mins. There were very few interruptions to the interviewing process apart from when the telephone or the door bell momentarily rung. However, there were no significant disruptions to the interviews.

Overall, there were few concerns and the interviews appeared to run smoothly with most of the participants being interviewed at home. A particularly positive observation was that the reception was overwhelmingly warm. Participants appeared highly enthusiastic and were looking forward to being interviewed. It was evident that participants who were interviewed at home found the environment more homely, stimulating and relaxing and were more confident than those interviewed at the GP Surgery. The home environment may play a part in enabling participants to relate experiences and opinions more openly and honestly (Parkman, 1996). However, as more interviews were conducted, a pattern begun to emerge and the influence of the home environment on the interviews became more apparent. A common observation was the size of these homes (flats). Most of the flats were so small that the risk of intrusion and invasion of privacy was considerable (Stalker, 1998). Issues of confidentiality were made clear beforehand and I had expected or would have preferred to interview members of each dyad separately.

Unfortunately this was not possible in some cases; there were three occasions where this was impracticable and very difficult due to the nature and size of these flats. The living room, bed room and the kitchen were almost together, similar to what is commonly referred to as 'bed-sits'.

I considered it both unethical and unprofessional to suggest one of the pairs to find a place whilst the other was interviewed. As a researcher, I assumed the position of a 'stranger' or a guest in the home with limited choices where there was no alternative space for the interview to take place. Therefore, although the study aimed to access the individuals' views regarding communication on a few occasions, it appeared as though the pair was interviewed together. This was because at times it was quite possible for the other person to hear the interviews even when he or she was in a neighbouring area due to the proximity and the nature of these flats. Upon reflection there were some responses which I was not entirely certain about. For example, I wondered whether the responses that were provided were not biased or influenced by the presence of the other person (service user or the carer). If I had interviewed each of the pair separately, that is at different places, would the responses be the same or differ.

Nevertheless, it was also possible that the presence of both members of the pair may have enhanced the richness of the data by enabling a more in-depth revelation of participants' experiences regarding communication with health and social care professionals. However, I had a feeling that this may be different when the issue/phenomenon is regarding the service users and the carers. The presence of the carer may inhibit the service user's construction of reality regarding communications, in particular if it relates to the carer (possibly for fear of retribution). Individuals may feel uncomfortable giving negative remarks about each other. Nevertheless, there were also many positive aspects to draw from this situation. In particular, in some cases, the pair (service user and carer) appeared to be very

inter-dependent and during the interviews, clarification was sought and responses validated from each other. These observations were recorded in the researcher's field notes. In conclusion, it is evident that interviewing in the community is associated with unpredictable circumstances that can impact on the quality of the interviews, such as the presence of others and the interruption of telephone and door bell. However, as a researcher, there was a need to maintain a trusting relationship and accept participants' accounts of their experiences as the truth in sharing their views regarding communication with health and social care professionals.

### 3.7 Criteria for assessing the trustworthiness

The criteria for assessing the rigour of a qualitative study are still debated. It is argued that the methodological rigour of qualitative study is confounded by the diversity and lack of consensus about the rules to which it ought to conform (Sandelowski, 1986). Other scholars argue whether criteria should be applied at all; and if so which criteria should be used and given the adopted criteria, and how these should be assessed within a particular study (Murphy et al., 1998). In the past, the validity and reliability of qualitative study was measured in relatively conventional terms. However, from the 1980s qualitative researchers began to take different views (LeCompte & Preissle 1993 in: Murphy et al., 1998). Whilst some qualitative researchers argued that the conventional criteria should be used to judge qualitative studies (Kirk and Miller, 1986), critics claimed that it is not possible to maintain common criteria of evaluation for both qualitative and quantitative research (Smith, 1984).

Other researchers claimed that the criteria for assessing the rigour of a particular qualitative work should be paradigm specific and argued that the conventional validity and reliability criteria should be replaced with criteria that are more congruent with the tenets of qualitative studies (Lincoln and Guba, 1985). These authors proposed a criterion for judging the rigour of naturalistic inquiry known as *Trustworthiness*

(Lincoln and Guba, 1985). This criterion has been widely accepted and applied by numerous researchers (Beck, 1993; Koch, 2006; Sandelowski, 1986). To establish trustworthiness in qualitative study Lincoln & Guba suggested the criteria of: credibility, transferability, dependability and confirmability as shown in Table 3 below.

**Table 3. Criteria for Trustworthiness**

| Conventional criteria |                   | Naturalistic Inquiry |
|-----------------------|-------------------|----------------------|
| Truth value           | Internal validity | Credibility          |
| Applicability         | External validity | Transferability      |
| Consistency           | Reliability       | Dependability        |
| Neutrality            | Objectivity       | Confirmability       |

Congruent with the naturalistic paradigm used in this study, these criteria of trustworthiness (see Table 4 below) were employed to evaluate the rigour of the data collection and interpretations as demonstrated below.

### *3.7.1 Credibility*

It is asserted that understanding the concept of validity is dependent on understanding of the beliefs regarding the nature of reality (Cohen and Crabtree, 2008). The positivists' concept of 'true value' is based on the assumption that there is one single tangible reality and that knowledge is knowable which the researcher tries to prove albeit sometimes imperfectly (Cohen and Crabtree, 2008; Lincoln and Guba, 1985). However, naturalists refer to this as 'naive realism' and reject the notion that 'truth' or reality is single. Instead, realities are multiple, constructed and there is no ultimate bench mark to target but the accurate representations of those multiple constructions is emphasized (Lincoln and Guba, 1985). It is argued that the hallmark of high-quality research is to produce rich, substantive accounts with strong evidence for inferences and conclusions and report the lived experiences of those studied and their perspectives on social reality, while acknowledging that these realities could be multiple and complex and that the portrayal of these experiences is not value free

(Cohen and Crabtree, 2008; Lincoln and Guba, 1985). Therefore, it is argued that plausibility and accuracy are crucially important to good qualitative research (Cohen and Crabtree, 2008).

In this study, the goal is; understanding and providing a meaningful account of the complex perspectives regarding communication between service users, carers and health and social care professionals. Strategies used to achieve credibility include: reflectivity, triangulation, member checks, prolonged-engagement, negative case analysis and peer-debriefing.

*Reflectivity:* In this study, the preceding section 3.6.4 is devoted to reflection of the interviewing process. In addition, self-awareness of the researcher's own cultural and professional background is important in the interpretation of participant views, perspectives and experiences regarding communication with health and social care professionals. Furthermore, interviews were tape-recorded with participant consent to capture the participants' multiple views regarding communication. Interviews were transcribed verbatim.

In addition, field notes and a research diary were also kept. These contained jotted and reflective notes during and after the interviews (see Appendices 12 and 13). In particular, two carers declined for their interviews to be taped but, agreed for the researcher to take notes. These were all transcribed and analysed.

In the transcribing process, constructions or expressions that were not clear or deeply rooted in the local dialect were double checked for meaning from experienced colleagues and supervisors.

*Triangulation:* this is defined as the combination of two or more theories, data sources, methods, or investigators in one study of a single phenomenon (Denzin, 1989). It is claimed that triangulation serves two main objectives. Firstly, for the purpose of confirming the



accuracy of data (Denzin, 1989) in order to minimize any threat to validity (Shih, 1998). Secondly, triangulation is used for the purpose of completeness for example to capture a more complete, holistic and contextual portrayal of the phenomena. Two forms of triangulation were applied in this study (1) Data triangulation. This involved semi-structured interviews with service users and carers regarding communication with healthcare professionals and (2) Method triangulation. Carer communication diaries were used as a credibility check for the carer interview data.

*Member checks:* One popular method of establishing credibility is by consulting participants themselves and asking them to read and discuss the constructions derived from the analysis (Koch, 2006). However, other researchers have claimed that member checking can be problematic, arguing that it does not make sense to ask study participants to check and verify audio-recorded transcribed data (Cohen and Crabtree, 2008). This may be attributable to limited recall of what was said during the interviews. Even when participants do recall, a number of factors may lead to discrepancies between their recall, transcribed data and the preliminary and final findings (Cohen and Crabtree, 2008).

In this study, member checking was not undertaken due to a number of reasons. First, the nature of the participants involved: people with learning disabilities with epilepsy may have communication difficulties, cognitive impairment and may have limited recall. Thus, it was considered inappropriate to engage in member checking as a test of credibility. Second, it is argued that the essence of qualitative analysis is to organise themes to produce higher level synthesis and individuals may not recognise their contributions (Cohen and Crabtree, 2008) as this may require higher cognitive functioning. However, people with learning disabilities may have cognitive impairments. Third, the focus of this study is considered as a sensitive and a highly emotive area. For example, stigma of epilepsy features

strongly as a barrier to communication. Some participants reported their preference not to talk about their epilepsy, because talking about epilepsy is considered unpleasant and reminds them of their past experiences. Therefore, it was considered inappropriate to continue to trigger issues relating to stigma. Instead, a summary of findings would be given to participants but detailed feedback would not be provided unless requested by the individual.

*Prolonged engagement:* The naturalistic paradigm requires the researcher to spend sufficient time in the field to understand and to familiarize him/herself with the context of the study. Prolonged engagement mainly involves spending enough time to become oriented to the situation (Lincoln and Guba, 1985). Although time investment is relative, it is argued that it should be long enough to enable understanding of the study context and culture (Lincoln and Guba, 1985). The researcher has worked in the field of learning disabilities as a mental health nurse for a significant period of time and this has facilitated his familiarization with the learning disabilities population. Also, the development of collaborative relationships, gaining access, for example as 'prior ethnography' (outlined earlier) all promoted the researcher's understanding of the study population. Prolonged engagement required the commitment of time and resources. About 90% of the project budget annual allocation over the past three years has been spent mainly on field activities. For example, the process of gaining informed consent involved numerous contacts with the study setting and participants. Numerous field visits at least twice a week, were made to the study setting to interact with potential participants prior to and during, data collection. In addition, all the methods employed in this study were piloted prior to being applied.

*Negative case analysis:* Negative cases are instances that contradict the theory being developed during the analysis of data. It involves continuous revision of the hypothesis until it accounts for all known

cases without exception (Lincoln and Guba, 1985). All individual transcripts and interpretations were revisited several times to ascertain their 'fitness' in the emerging model. Deviant cases were identified and followed up in order to obtain a complete understanding why the phenomena are experienced or reported differently by participants. In accordance with the naturalistic paradigm with the emphasis on multiple realities, it is more than anticipated that one would encounter divergent perspectives regarding communication. Individuals' views regarding communications and their experiences regarding epilepsy were complex and varied. The communication needs of participant 'A' may vary significantly from the other participants. In fact, for some service users, their concerns and experiences may not be related to communications at all. For example, stigma was variously reported by service users, family carers and care workers. Whilst some service users have not reported any concerns regarding epilepsy, others regarded it as a significant barrier to communication. Similarly, family carers were more concerned regarding seizures and stigma than care workers. This may reflect differences in emotional feelings in their relationship with the service user.

*Peer debriefing:* Lincoln & Guba, (1985 page 308) defined peer debriefing as a process of exposing oneself to a disinterested peer in a manner paralleling an analytical session for the purpose of examining aspects of the inquiry that might otherwise remain only explicit to the inquirer. Debriefing is claimed to serve four purposes: (i) it helps keep the inquirer 'honest' by probing for meaning, bias, and understanding; (ii) It provides the opportunity to test working hypotheses that may be emerging in the investigator's mind; (iii) it provides the opportunity to develop and test the next steps in the emerging methodological design; and (iv) it provides evaluators or researchers with an opportunity for catharsis (Lincoln and Guba, 1985). In this study, the collaboration team, (the Managed Clinical Network for epilepsy for the study locality), in particular the community learning

disabilities team were actively involved and input considerably regarding the design and data collection strategies. In addition, regular supervisory meetings were held at least once a month to discuss aspects of the study. A digital poster of preliminary findings of the study was presented at The Scottish School of Primary Care national conference in Stirling and to colleagues in the university. Aspects of the study findings were presented to colleagues at the school's research seminar.

### *3.7.2 Transferability*

Transferability is said to be dependent on the degree of similarities between two contexts; the 'fittingness' of the two contexts to permit the possibility for a transfer (Koch, 2006). It is argued that phenomena are intimately tied to the times and contexts in which they are experienced (Murphy et al., 1998). Therefore, an adequate description of the context is relevant to allow judgement to be made whether the study is transferable or can be replicated in a different context.

As mentioned earlier, this study was undertaken in a certain geographic location within Scotland where the culture and beliefs within this particular locality may differ from other settings across the UK population. Moreover, detailed description regarding how the study has been conducted, for example the methodology and design are all made explicitly clear and signposted throughout. Limitations to the study are acknowledged in a later chapter of this thesis. For example, only people with *mild* learning disabilities were recruited for this study. Their communication needs and expectations may differ from individuals with moderate to severe learning disabilities. For this study to be deemed transferable would be heavily dependent on the context under which this study was undertaken.

### 3.7.3 Dependability

Naturalistic researchers used the term dependability rather than consistency and reliability. It is argued that one way of demonstrating dependability is to ensure that the research process is auditable (Lincoln and Guba, 1985). A study and its findings are auditable when another researcher can follow the decision trail used by the researcher (Sandelowski, 1986). A decision trail provides a means for the researcher to establish audit trail linkage. In this study, all methodological, theoretical and analytical decisions are made explicitly clear to allow other investigators to follow the lines of reasoning of the researcher (Koch, 2006) and possibly, audit the study. The study rationales are provided to justify any decisions or interventions.

### 3.7.4 Confirmability

Confirmability requires a demonstration of how the interpretations and conclusions have been made. According to the naturalistic paradigm, confirmability is established when credibility, transferability and dependability are achieved. In summary, this requires signposting in the thesis and the entire study should flow as an audit trail (Koch, 2006). In this study the chronology of study from introduction to conclusions are clearly signposted. Table 4 below outlines the strategies used to examine the trustworthiness of this study.

**Table 4. Strategies used to establish trustworthiness**

| Criteria        | Measures used   |
|-----------------|---|
| Credibility     | Triangulation, Prolonged engagement, Peer debriefing, negative case analysis, Log books and field notes/diary, audio-tapping, Reflexivity (Self-awareness), verbatim transcripts. |
| Transferability | In-depth or thick description that will facilitate comparison to inform the possibility of a transfer or replication  |
| Dependability   | In-depth description of research methodology enabling auditing of decision processes and signposting  |
| Confirmability  | Triangulation, in-depth description, audit trail, peer debriefing.  |

## Chapter 4: Data Analysis

### 4.1 Introduction

The analysis of qualitative data is both a challenging and an exciting task (Ritchie and Lewis, 2003). Although this chapter is entitled as analysis, the analysis of qualitative data is said to be cyclical and concurrent with the data collection process (Tech, 1990). Data analysis began as soon as the first data were collected and ended when the findings of the study are written up (Ritchie and Lewis, 2003; Tech, 1990). The two processes were complementary as they informed each other or even drove each other on (Miles and Huberman, 1994).

Moreover, it has been asserted that a central difficulty in the use of qualitative data is that methods are not well defined and the analysts of the data have very few guidelines for protecting against biased conclusion for the audience (Murphy et al., 1998). However, it is claimed that within the last two decades, this trend has changed significantly. There has been better documentation regarding qualitative data analysis approaches with an increase in publications that explore the theoretical and practical issues of qualitative data analysis (Spencer et al., 2003). Nevertheless, it is argued that although there is now more clarity regarding how qualitative data are 'managed', there remains little rigour regarding how the findings are generated from the data collected (Ritchie and Lewis, 2003). Following the advent of technology, Computer Assisted Qualitative Data Analysis software (CAQDAS) has become a popular tool in the field of qualitative data management. However, these software packages also have their strengths and weaknesses. It is asserted that one of the most useful functions of the CAQDAS is in the processing of large chunks of data sets. However, claims that using CAQDAS packages to support data analysis enhances the rigour of the analysis have been criticized. Some of these criticisms appear to be

both technical and epistemological in origin. For example, concerns have been expressed regarding the risk of losing data through operator error and the choice of the individual software and its implementation may lead to difficulties (Murphy et al., 1998).

The naturalistic paradigm holds the axiom that the knower and the known are interactive and inseparable. The emphasis of the human as the main data collection tool makes the use of CAQDAS more incongruent with the philosophical underpinning of this study. However, it is the researcher's conceptual skills that are needed to shift, order, synthesise and interpret the data and it is argued here that no software can replace these human properties (Ritchie and Lewis, 2003). The interview lengths in this study are generally short ranging from 15-30mins for service users and about 45mins for carers. This was readily managed by the researcher.

## 4.2 Analytical approach utilized in this study

As mentioned earlier, this project is an exploratory study and aims at producing descriptive findings that encompass all the participants' views and experiences regarding communication, allowing limited comparison. The target audiences include: carers, health care professionals, academics and policy makers. The analysis is aimed at providing descriptive answers about the context for social policies regarding communications with people with learning disabilities, carers and health care professionals.

Framework analysis is widely regarded suitable for the analysis of applied policy research (Pope and Mays, 2006). In this study, the analyst will apply the thematic framework as outlined by Spencer and colleagues (Spencer et al in: Ritchie and Lewis, 2003). The framework analysis approach is systematic and designed for transparency so that the analytical processes and interpretations can be viewed and assessed by people other than the researcher (Pope and Mays, 2006). It is claimed that the analysis process is similar to thematic analysis

but tends to be more explicit and more informed by prior reasoning (Pope and Mays, 2006). This approach to qualitative analysis involved the systematic processes of shifting, charting and sorting materials according to categories and key themes (Bryman and Burgess, 1994). The framework analysis approach is characterised by five key stages: 1. Familiarization, 2. Identifying a thematic framework, 3. Indexing, 4. Charting, 5. Mapping/interpretation. Although these stages may appear distinct, they are all highly interconnected (Bryman and Burgess, 1994).

#### *4.2.1 Familiarization*

Qualitative materials are said to be invariably, 'voluminous', 'unstructured' and 'unwieldy' and thus, need to be processed (Bryman and Burgess, 1994). This process of transcribing audio-taped interviews and field notes were factored into the researcher's schedule immediately after each set of data was collected. Contrary to the suggestions that 'selective' and 'partial' transcription is sufficient for a qualitative study (Burgess in: Bryman and Burgess, 1994) all the interviews were transcribed verbatim. This facilitated familiarization with the data and allowed the unpacking of the multiple realities as expressed by participants within the context of their lived experiences. This process of immersion in the data, which involves listening to tapes, reading over the transcripts and taking notes of recurrent themes, was continued until it was felt that all the diversity and circumstances have been unpacked. A range of themes emerged from the interview data, relating to service users' communications with carers and health care professionals for example, verbal communication, non-verbal communication or both, other forms of communication, listening, understanding, time, involvement, acquiescence, pace, epilepsy, medication and side effects, information, fear/stigma, impairments (physical and cognitive) workload, domestic chores, social events, medical appointments. These were all identified and noted down.



#### *4.2.2 Identifying a thematic framework*

The familiarization phase was not only characterised by gaining an overview of the richness, depth and range of diversities in the data but the process of abstraction and synthesis/conceptualization also took place (Bryman and Burgess, 1994). Although it is argued that selective familiarization is possible (Spencer et al, in: Ritchie and Lewis, 2003), each individual transcript was thoroughly examined. This involved systematically reading and re-reading each interview transcript over and over, highlighting important statements recording and grouping recurrent themes, patterns, and ideas as they emerge from the data (Gillham, 2000): in this case, themes relating to participants' views and perceptions regarding communication with health and social care professionals and relating to epilepsy. Once all the transcripts were 'exhausted' with all recurrent themes and patterns noted, the lists of identified themes or groups of themes were used to develop a conceptual framework comprising categories of main themes and sub-themes (see Table 5 below). Although the construction of the framework appeared mechanical, it involved logical and intuitive processes (Bryman and Burgess, 1994). The thematic framework that emerged was based on emergent issues and themes raised by participants and also the incorporation of issues identified earlier (Bryman and Burgess, 1994). These issues were informed by the project aim and objectives and introduced through the interview schedule (topic guide).

After the initial application of the framework to the transcripts, it was evident that there was the need for some revision of the initial framework. For example, there were some statements or phrases that could be interpreted differently and others could not be located in the framework. Thus the framework was reviewed several times, editing the main themes and sub-themes until all the emergent themes and sub-themes were accommodated.

The final framework comprises four broad categories of main themes and fifteen sub-themes. It includes a section labelled 'other themes' for significant but unrelated themes or for general comments regarding the themes. Textual terms were then assigned to differentiate the individual categories, themes, and sub-themes (see Table 5 below). These textual terms reflect the essence of the emergent theme or sub themes (Spencer et al, in:Ritchie and Lewis, 2003). There were no differences in themes specific to either service users or carers emerging from the interviews.

**Table 5. Extract of the thematic framework showing categories of main themes and sub-themes regarding service users communication with carers and health care professionals**

| <b>1</b> | <b>SERVICE USER COMMUNICATION WITH CARER/S</b> |                     | <b>2</b> | <b>SERVICE USERS COMMUNICATION WITH HEALTH PROFESSIONALS</b> |                     |
|----------|--|---------------------|----------|--|---------------------|
|          | <b>Methods of communication</b>                | <b>Labels</b>       |          | <b>Methods of communication</b>                              | <b>Labels</b>       |
|          | Verbal communication                           | Comm. verbal        |          | Verbal communication   | Comm. verbal        |
|          | Non-verbal or both                             | Non-verb. comm      |          | Non-verbal or both   | Non-verb. comm      |
|          | <b>Communication exchanges</b>                 |                     |          | <b>Communication exchanges</b>                               |                     |
|          | Understanding                                  | Underst. comm       |          | Understanding  | Underst. comm       |
|          | Listening                                      | Listen. comm        |          | Listening  | Listen. comm        |
|          | Pace/timing                                    | Pace/time. comm     |          | Pace/timing  | Pace/time. comm     |
|          | Acquiescence                                   | Acquies. comm       |          | Acquiescence   | Acquies. comm       |
|          | Other issues                                   |                     |          | Other issues   |                     |
|          | <b>Communication needs/functions</b>           |                     |          | <b>Communication needs/functions</b>                         |                     |
|          | Social activities                              | Comm. soc           |          | Social activities  | Comm. soc           |
|          | Epilepsy/medicines                             | Epi. meds/info      |          | Epilepsy/medicines   | Epi. meds/info      |
|          | Giving information                             | Info. comm          |          | Giving information   | Info. comm          |
|          | <b>Barriers to communication</b>               |                     |          | <b>Barriers to communication</b>                             |                     |
|          | Lack of vocabulary                             | Vocabs. comm        |          | Lack of vocabulary   | Vocabs. comm        |
|          | Carer Info overloads                           | CarerInfo. overload |          | Carer Info overloads   | CarerInfo. overload |
|          | Physical/cognitive disability                  | Disa. comm          |          | Physical/cognitive disability                                | Disa. comm          |
|          | Stigma   | Stigma. comm        |          | Stigma   | Stigma. comm        |
|          | Other issues                                   |                     |          | Other issues   |                     |

| <b>3</b> | <b>CARER COMMUNICATION WITH SERVICE USERS</b> |                     | <b>4</b> | <b>CARER COMMUNICATION WITH HEALTH PROFESSIONALS</b> |                     |
|----------|---|---------------------|----------|--|---------------------|
|          | <b>Methods of communication</b>               |                     |          | <b>Methods of communication</b>                      |                     |
|          | Verbal communication                          | Comm. verbal        |          | Verbal communication                                 | Comm. verbal        |
|          | Non-verbal or both                            | Non-verb. comm      |          | Non-verbal or both                                   | Non-verb. comm      |
|          | <b>Communication exchanges</b>                |                     |          | <b>Communication exchanges</b>                       |                     |
|          | Understanding                                 | Underst. comm       |          | Understanding  | Underst. comm       |
|          | Listening                                     | Listen. comm        |          | Listening  | Listen. comm        |
|          | Pace/timing                                   | Pace/time. comm     |          | Pace/timing  | Pace/time. comm     |
|          | Acquiescence                                  | Acquies. comm       |          | Acquiescence   | Acquies. comm       |
|          | Other issues                                  |                     |          | Other issues   |                     |
|          | <b>Communication needs/functions</b>          |                     |          | <b>Communication needs/functions</b>                 |                     |
|          | Social activities                             | Comm. soc           |          | Social activities                                    | Comm. soc           |
|          | Epilepsy/medicines                            | Epi. meds/info      |          | Epilepsy/medicines                                   | Epi. meds/info      |
|          | Giving information                            | Info. comm          |          | Giving information                                   | Info. comm          |
|          | <b>Barriers to communication</b>              |                     |          | <b>Barriers to communication</b>                     |                     |
|          | Vocabulary                                    | Vocabs. comm        |          | Lack of vocabulary                                   | Vocabs. comm        |
|          | Carer Info overloads                          | CarerInfo. overload |          | Carer Info overloads                                 | CarerInfo. overload |
|          | Physical/cognitive disability                 | Disa. comm          |          | Physical/cognitive disability                        | Disa. comm          |
|          | Stigma  | Stigma. comm        |          | Stigma   | Stigma. comm        |
|          | Other issues                                  |                     |          | Other issues   |                     |

### 4.2.3 Indexing

Contrary to the suggestion that it is possible to exclude the indexing stage, for example due to the precise nature of the interview schedule, and move on to synthesize the data (in:Ritchie and Lewis, 2003), in this study, the thematic framework was systematically applied to each individual transcript. This further facilitated the researcher's familiarization with the data as a whole. It involved reading and making sense of, or interpreting, each statement and phrase, deciding what it is about and which part of the framework it applies to. The indexing references were then manually recorded within and along the margins of each transcript (Bryman and Burgess, 1994;Pope and Mays, 2006). This also involved the use of tacit knowledge. After the preliminary application, the framework was reviewed to accommodate missing themes or additional categories. This process was continued until all the transcripts were completely indexed and accounted for almost every statement (see Figure II below).

**Figure II. Example of indexed or labelled transcript**

|   |   |
|---|---|
| Communication strategies/methods<br>Verbal/non-verbal eg<br>(Verbal,comm) | Q: How do you communicate/talk with her?... eg by words through voice or signs like these?<br>A: <i>Well it depends on the mood like, we will not argue about anything, in fact of yet two years we have been married we have not had an argument.</i><br>Q: When communicating with her, do you normally use words with your voice or signs like these?<br>A: <i>No, Is words she understands like, but also I use my hands you know.</i><br>..... |
| Function or purposes of communication,<br>eg, social events               | Q: What kind of things do you talk about with her?<br>A: <i>Everyday sort of things ....politics or whatever, papers, appointments with mates eg in Banff to see McDonald brothers.</i><br>Q: What about medicines and epilepsy issues?<br>A: <i>Well I take my tablets everyday. Two in the morning and three at night. Have been given pain killers from</i>  |

|   |  |
|---|--|
|   | doctors which I take.  |
| Communication style   | <p>Q: Do you talk to her the same kind of ways you will talk to your friends?</p> <p>A: No! If am talking to a friend is my usual "banter" but usually softer to her.</p>  |
| Understanding<br>(underst.com)                                | <p>Q: What does she do to let you know what you are talking about?</p> <p>A: Yes, certain subjects like, if there is anything am going about, I will tell her such and such and we will talk about it.</p> <p>Q: Is it easy/hard to know what she is talking about?</p> <p>A: Is easy</p>  |
| Familiarity   | <p>Q: Are there reasons for any communication or talking difficulties?</p> <p>A: No. even though she does come from Banff and I come from different part of the world we do understand each other.</p>   |
| Involvement   | <p>Q: Do you get the chance to say what you think?</p> <p>A: Yes, will say whatever is on my mind like.</p>  |
| Communication exchanges                                       | <p>Q: are there any issues/things you find difficult/hard talking about or discussion with her.... eg about seizures/epilepsy, medicines?</p> <p>A: No, not really, we have got the same sort of body language but we can speak about anything.</p>  |
| communication regarding epilepsy and medication<br>(meds.com) | <p>Q: You don't have problems discussing epilepsy and medicines with her?</p> <p>A: No she knows I have epilepsy but she never seen it but is not a bother.</p>  |
| Stigma relating to Epilepsy<br>(Epilepsy.com)                 | <p>Q: How do people treat you if they know you have epilepsy?.... Do you think you are treated differently?</p> <p>A: I suppose they think something about it like but I can just say I have got epilepsy and let them get on with it. I will not beat about the bush like, If there is anything bad about it, say it, and if they don't just hold their tongue.</p> |

|   |  |
|---|--|
| <p>Understanding/<br/>Knowledge</p>               | <p>Q: But, do you think you are treated differently?<br/>A: No<br/>Q: Does he/she understand epilepsy?<br/>A: "She would like to know more about it as I would like".<br/>"aaaa, she would like to know more about it". Or even get somebody like yourself I think, Can I ask you this who are you classed as? And you think .... Will need to know more about epilepsy? Yes, she would like to know more about it "and would she get"? "That is what she needs to do like to be aware and learn something about epileptic fits"</p>                           |
| <p>Knowledge/<br/>Information<br/>(info.comm)</p> | <p>Q: Does she understand that you need to take your medicines?<br/>A: Yes, she does like, if I forget she would say have I taken my tablets and I will say either yes or no.</p>  |
| <p>Communcation<br/>Regarding medication</p>      | <p>Q: In the last two weeks, have you talked about or discussed epilepsy medicines issues?<br/>A: Well they come up and we discuss them. I know what I have to take and if I have not taken I would just accept it. Well if I didn't accept them from the age of 16 that is how long I have been taken it.<br/>Q: So what kind of things do you normally discuss with her regarding your medicine?<br/>A: Just curiosity whether I have taken my tablets or not.<br/>Q: With those discussions do you still have any problem with your medicine?<br/>A: No</p> |
| <p>Understanding/<br/>Listening/views</p>         | <p>Q: Do you think she listens to you?<br/>A: Yes<br/>Q: Does she understands and takes on board what you say?<br/>A: Yes, well so she says anyway<br/>Q: How do you know that she agree with you? Yes, Well so she let on anyway, she just let on as she does if she doesn't, tough..... (big laugh)</p>  |

#### *4.2.4 Charting*

Following indexing, the indexed materials (transcripts) were then used to construct a set of thematic charts; to build a bigger picture of the data as a whole where each main theme and its associated sub-theme/s can be interrogated further. Data were shifted from their original forms in the transcripts and rearranged according to the appropriate parts of the thematic framework to which they relate so that materials with the same content or properties are located together (Ritchie and Lewis, 2003). For example, methods of communication were sub-headed into verbal and non-verbal communication. Whilst listening, time and information provisions were all grouped under communication exchanges. Microsoft excel was adapted where each participant was plotted against each category/theme and the associated sub-themes. Two separate charts were created, one for service users' views regarding communication and the other for the carers.

The unique identifiers for all participants were maintained to enable a follow-up for more detailed interrogations and also for pairing up of the dyads (service user and carer) for a later comparative analysis. The charts were created according to how the study and the findings may be reported. All the main themes/categories and sub-themes were allocated the top horizontal columns and each participant allocated a row in the chart. There was also a column to indicate the population of the communication for example whether the views and experiences reported are between the service user and the carer or whether it relates to their communications with the health and social care professionals. The 'raw' and completed indexed materials from each transcript were then shifted and sorted into the appropriate index reference. Following this, the whole spread sheet and its content was then exported into a word document format for easy handling and further interrogation.



The first version of the chart was undeniably rich in textual data where there was high retention of the participants own words and views. Unlike the traditional 'cut' and 'paste' method, this charting also involved abstraction and synthesis (Bryman and Burgess, 1994;Pope and Mays, 2006). This stage of the analysis involved reading, synthesising and making interpretation of each participant's responses and views regarding communication with health and social care professionals under each theme and then summarizing the details, into the appropriate sections of the chart. This led to a complete synthesis of each service user and carers' views regarding their communications and also with health and social care professionals. Illustrative passages for use as possible quotations were referenced with the transcript page numbers which also permitted the tracking of significant statements to the original transcript at later stages of the analysis.

**Table 6. Example of a charted transcript**

**Categories (S&C=Service user and carer communication, S&D=Service user communication with doctors, S&N=Service user communication with nurses. Respondent=participant identifiers**

| RESPONDENT | CATEGORY | METHODS OF COMMUNICATION   |   | COMMUNICATION EXCHANGES   |   |                  |
|------------|----------|----------------------------|---|---|---|------------------|
|            |          | Verbal. comm               | Non-verbal or both                        | Listening/understanding/information provision   | User involvement e.g. views/ Choices.         | Others/ comments |
| PE         | S&C      | "Is words she understands" | Also when you use your hands and whatever | "Is easy even though she does come from [locality] and I come from different part of the world we do understand each other"pp10 "If I am talking to my friends is my usual banter but usually softer when talking to her" | "Yes, I will say whatever is on my mind" pp10 |                  |

| RESPONDENT | CATEGORY | METHODS OF COMMUNICATION |                    | COMMUNICATION EXCHANGES  |  |  |
|------------|----------|--------------------------|--------------------|--|--|--|
|            |          | Verbal. comm             | Non-verbal or both | Listening/understanding/information provision  | User involvement e.g. views/ Choices.                            | Others/ comments   |
| PE         | S&D      | Verbal                   |                    | "They are more listening than the doctors." They are more 'heat up' to what you are saying than the doctors" pp12. "Listen more to what you have to say, some of the doctors don't just listen, is just flowing over their heads" pp13. "Well, I get more information from a nurse than I would from a doctor" pp12. They go about it in a different way, they discuss first what is wrong with you whereas the doctors will tell you what is wrong with you" pp12 | "Now and again. Very rarely, I am just talking to you like" pp13 | However, communication does not affect what the service user do or affect the way he is cared for. |
| PE         | S&N      | Verbal                   |                    | "Nurse have more time for you than the doctors"  | No concerns  |  |

| RESPONDENT | CATEGORY | METHODS OF COMMUNICATION |   | COMMUNICATION EXCHANGES   |                                       |                                |
|------------|----------|--------------------------|---|---|---------------------------------------|--------------------------------|
|            |          | Verbal. comm             | Non-verbal or both  | Listening/understanding/information provision   | User involvement e.g. views/ Choices. | Others/ comments               |
| PT         | S&C      | Verbally with carers     | "I think we should try and not use a lot of words but some very few words along with the pictures" pp21 | "I find that if they speak on a one-on-one. If you got more than one-one you have got no communication with them" "If you have got like one-on-one is not too bad but if you got more than one-on-one then your brain can only take so much in at a time" |                                       |                                |
| PT         | S&D      | Verbal communications    |   | Participant expressed satisfaction regarding communication, however, advocated for the use of symbols and pictures to supplement spoken words. "I think we should try and not use a lot of words but some very few words along with the pictures" pp21    |                                       | Pressured speech due to asthma |

| RESPONDENT | CATEGORY | METHODS OF COMMUNICATION |                    | COMMUNICATION EXCHANGES  |                                       |                  |
|------------|----------|--------------------------|--------------------|--|---------------------------------------|------------------|
|            |          | Verbal. comm             | Non-verbal or both | Listening/understanding/information provision  | User involvement e.g. views/ Choices. | Others/ comments |
| PT         | S&N      | Verbal                   |                    | "They alter your medication and your brain can only take in so much at a time Jerry, you know" |                                       |                  |

| RESPONDENT | CATEGORY | METHODS OF COMMUNICATION |                    | COMMUNICATION EXCHANGES   |  |                  |
|------------|----------|--------------------------|--------------------|---|--|------------------|
|            |          | Verbal. comm             | Non-verbal or both | Listening/understanding/information provision   | User involvement e.g. views/ Choices.  | Others/ comments |
| PG         | S&C      | All verbal               |                    | "He is the person who knows what I am going through, he does listen. I see sometimes other people are not bothered listening to me even though we have meetings up here" pp 27. | Participant is able to express his views and wishes but feels they are not considered by others. "Yes he agrees with what I want to do but I feel controlled for some reasons, I am not sitting waiting till Thursdays and then go to my work, sitting doing nothing, I want to work from Monday to Friday, I am not sitting about" pp25 |                  |

| RESPONDENT | CATEGORY | METHODS OF COMMUNICATION |                    | COMMUNICATION EXCHANGES  |  |                  |
|------------|----------|--------------------------|--------------------|--|--|------------------|
|            |          | Verbal. comm             | Non-verbal or both | Listening/understanding/information provision  | User involvement e.g. views/ Choices.  | Others/ comments |
| PG         | S&D      | All verbal               |                    | <p>"Sometimes the doctors don't want anybody else, you feel like they have no time for you to speak to that is why you are holding things in, they don't want to listen, they are that busy but even if you say I want to sit and have a word they want you out of the door" pp27.</p> <p>"Sometimes looking away from you, there is no eye contact"pp27. "A little bit but they are not letting you know what they are thinking" pp27.</p> <p>"I do but I think I do frighten them. The way I speak to them, you would listen either or you would not do that with me like, I would sit for nearly a day and won't let anybody out and lot of folks don't like it. They are really scared of me, that is the only way they can listen" pp27</p> | <p>Service user is able to voice his concerns. "I do but I think I do frighten them. The way I speak to them, you would listen either or you would not do that with me like, I would sit for nearly a day and won't let anybody out and lot of folks don't like it. They are really scared of me, that is the only way they can listen" pp27</p> |                  |

| RESPONDENT | CATEGORY | METHODS OF COMMUNICATION |                    | COMMUNICATION EXCHANGES   |                                       |                  |
|------------|----------|--------------------------|--------------------|---|---------------------------------------|------------------|
|            |          | Verbal. comm             | Non-verbal or both | Listening/understanding/information provision                       | User involvement e.g. views/ Choices. | Others/ comments |
| PG         | S&N      | Verbal                   |                    | "Nurses have helped me when I was off for a week with my knee" pp27 |                                       |                  |



| RESPONDENT | CATEGORY | COMMUNICATION NEEDS  |  | BARRIERS TO COMMUNICATION |                |  |   |
|------------|----------|--|--|---------------------------|----------------|--|---|
|            |          | Comm.soc   | Epi/meds knowledge/info.   | vocabs. comm              | Phys/cog .comm | Stigma. comm   | Info/ time/ work overloads. comm  |
| PE         | S&C      | Everyday sort of things, politics or whatever, papers. We have made appointments to go and see McDonald brothers | "I take my tablets. Two in the morning and three at night". "She would like to know more about it as I would" and would she get? pp11. "That is what she needs to do, to learn something about epileptic fits"pp11. "They come up and we discuss them. Curiosity whether I have taken my tablets or not" |                           |                | Although service is aware of stigma is not considered a barrier to communication."I suppose they think something about it but I can just say I have got epilepsy and let them get on with it" pp11 | Limited knowledge and information regarding epilepsy could impact on communication." She would like to know more about it or even to get somebody like yourself" pp11 |
| PE         | S&D      |  | "I have been given pain killers from the hospital which I take. If I forget she would say have you taken your medicine and I would say either yes or no".  |                           |                |  | Limited consulting time   |
| PE         | S&N      |  |  |                           |                |  |   |

| RESPONDENT | CATEGORY | COMMUNICATION NEEDS   |  | BARRIERS TO COMMUNICATION |   |   |  |
|------------|----------|---|--|---------------------------|---|---|--|
|            |          | Comm.soc  | Epi/meds knowledge/info.   | vocabs. comm              | Phys/cog .comm  | Stigma. comm  | Info/ time/ work overloads. comm   |
| PT         | S&C      | Participant communicates on wide range of issues including how they are feeling and how the day has been spent. | "I don't go to a lot of discos because the thing is there could be flashing light or strobe lighting from an angel. They say is not very good for people with learning disabilities" pp 16. "The warning is, it could give you butterfly in your stomach or a funny taste in your mouth. Carer's knowledge of epilepsy is mostly superficial and variable. Understanding of epilepsy is akin to understanding of learning disabilities". |                           | Participant also has asthma and leads to breathlessness | Participant feels she is treated differently because of her learning disabilities and epilepsy. They are actually taking the 'make out of you' and a lot of people don't like that. | Multiple carers, communication at the same time, lack of person-centred care, no one-on-one. The use of long words and the over reliance on spoken words, lack of pictures and symbols to augment communication" Sometimes I find that I get on well more with a lady than I do with a man" pp18 |

| RESPONDENT | CATEGORY | COMMUNICATION NEEDS |  | BARRIERS TO COMMUNICATION |                |              |                                  |
|------------|----------|---------------------|--|---------------------------|----------------|--------------|----------------------------------|
|            |          | Comm.soc            | Epi/meds knowledge/info.   | vocabs. comm              | Phys/cog .comm | Stigma. comm | Info/ time/ work overloads. comm |
| PT         | S&D      |                     | <p>"They have put a stop to my other tablets that I used to take but I don't know why, I think.... (nurse) said the learning disabilities team agreed on that but when I spoke with my mum my mum said I was best taking two at lunch time instead of the one" pp19. I find my doctor very good with me don't get me wrong but "I find it very difficult sometimes you have a very bad back problem, I use to get really good pain killers for bad backache but they have taken out these pills that I used to. They don't have any side effects with my medication but they have taken them off. Besides these nurses and doctors are very good with me".</p> |                           |                |              |                                  |

| RESPONDENT | CATEGORY | COMMUNICATION NEEDS  |   | BARRIERS TO COMMUNICATION |                |              |   |
|------------|----------|--|---|---------------------------|----------------|--------------|---|
|            |          | Comm.soc   | Epi/meds knowledge/info.  | vocabs. comm              | Phys/cog .comm | Stigma. comm | Info/ time/ work overloads. comm  |
| PT         | S&N      |  |   |                           |                |              |   |
| PG         | S&C      | Communications between service user and carer are largely dependent on employment issues, social activities including shopping | There is very little discussion with carer regarding epilepsy and medication management. Although he thinks the carer knows he needs to be taking his medication, there is no carer involvement at all."No, we don't speak about it at all" pp26. Service user reported dissatisfaction with staff regarding work leading to anger and frustration which can lead to more seizures. |                           |                |              | There is no reported barrier to communication with carer. Stigma is reported among peers at work but this does appear to be a barrier to communication. |

| RESPONDENT | CATEGORY | COMMUNICATION NEEDS |   | BARRIERS TO COMMUNICATION |                |              |  |
|------------|----------|---------------------|---|---------------------------|----------------|--------------|--|
|            |          | Comm.soc            | Epi/meds knowledge/info.  | vocabs. comm              | Phys/cog .comm | Stigma. comm | Info/ time/ work overloads. comm   |
| PG         | S&D      |                     | All communication needs of service user are work-related, money, the need to get a full time job, driving license although all these could be counter-productive to his seizures and his finances."I need to get more jobs but I am being held back. I want to get out in the morning, go to work and come and not just sitting about. No driving license and all that. If it builds up it may affect my epilepsy but I don't want that" pp28 |                           |                |              | Poor listening and work overload. Sometimes looking away from you. There are no eye contacts. They are that busy, they have no time like five minutes, no pp27 |
| PG         | S&N      |                     |   |                           |                |              |  |

#### *4.2.5 Mapping/synthesis and interpretation*

After shifting and charting all the data set according to the appropriate themes, the actual interpretation of the whole data set now begins. Distinct characteristics, views and experiences regarding communication and epilepsy related issues reported by service users and carers were pulled together and summarized. This involved the systematic detection of, and searching for, patterns and relationships within and between themes (Ritchie and Lewis, 2003), comparing and contrasting the views and perceptions, accounts and experiences regarding communication and epilepsy related issues. These pieces of information were thus drawn together to form a bigger picture (Bryman and Burgess, 1994).

The process involved reading down the particular column across each case and distilling the range of issues that exist. Analytical reasoning in this case often involved jumping ahead and returning to earlier ideas or transcripts to validate or distil more meaning (Bryman and Burgess, 1994). At this point, several versions of the charts were synthesised as some categories needed to be split to accommodate the new ideas, meanings or interpretation of themes that emerged. On occasion, some of the sub-themes were so similar in meaning that they needed to be combined or headed differently. This process also involved the use of intuition and imagination (Bryman and Burgess, 1994). This process of interpretation involved the 'why' questions about each theme (what it is about) and conceptualizing it into a higher level order.

The final version of the chart is a complete synthesis of all participants' views regarding communication (both positive and negative) with health and social care professionals. Following this coloured pens were used to mark and log these multiple and divergent views as reported by participants regarding communication and epilepsy related issues (see Table 7 below). This final stage of

interpretation reflected the project aims and objectives (Pope and Mays, 2006). It involved going back to the originally stated aims and objectives of the project and making comparison to ensure that the study objectives (see Page 9) were addressed. Quotations were selected to validate the themes identified and also to be indicative of how participants described their views regarding communication and epilepsy related issues with health and social care professionals.

Finally, the emerging themes and sub-themes of the findings were synthesized and summarised (see Table 8).

**Table 7. Mapping and interpretation**

**S&C, S&D and S&N are communication between Service user and carers, Service user and doctors, Service user and nurses.**

**Respondent=participant identifiers**

| RESPONDENT | CATEGORY | SERVICE USER WAYS (METHODS) OF COMMUNICATING WITH CARERS AND PROFESSIONALS. |   | SERVICE USERS' VIEWS/EXPERIENCES OF COMMUNICATION   |   |   |
|------------|----------|---|---|---|---|---|
|            |          | Verbal. comm  | Non-verbal or both                                | Perceptions of communication with carers and professionals.   | Explicit/implicit interpretation.                                   | Others/ comments  |
| PI         | S&C      | "I just talk to her" pp1. "She just talk to me" pp1                         | "I use my hands such as moving my hands you know" | "She surely listens to me, she will sit down listen and she will ask me questions" pp5<br><br>"Oh yes I do get the chance to say my mind" pp4                       | engagement eg listening and understanding                           |   |
| PI         | S&D      | Mostly verbal means   | Also gesture with hands                           | "I don't have any problems with the doctors and nurses, I often joke and laugh with them" pp5<br><br>"Yes they tell me how it happens. Aye, they do...They have to" | Engagement:<br>Positive/appropriate humour<br><br>User involvement? |   |
| PI         | S&N      | The same as with the doctors  | The same as with the doctors                      | "I don't have any problems with the doctors and nurses, I often joke and laugh with them" pp5   | Engagement: Positive facilitates<br>humour communication            | Service user is generally happy with communications with nurses |



| RESPONDENT | CATEGORY | SERVICE USER WAYS (METHODS) OF COMMUNICATING WITH CARERS AND PROFESSIONALS. |   | SERVICE USERS' VIEWS/EXPERIENCES OF COMMUNICATION  |   |                  |
|------------|----------|---|---|--|---|------------------|
|            |          | Verbal. comm  | Non-verbal or both                        | Perceptions of communication with carers and professionals.  | Explicit/implicit interpretation.   | Others/ comments |
| PE         | S&C      | "Is words she understands"  | Also when you use your hands and whatever | "Is easy even though she does come from Banff and I come from different part of the world we do understand each other"pp10<br>"If I am talking to my friends is my usual 'banter' but usually softer when talking to her". "Yes, I will say whatever is on my mind" pp10   | Styles of communication for different people.<br><br>Assertiveness?   |                  |
| PE         | S&D      | Verbal  |   | "They are more listening than the doctors. They are more 'heat up' to what you are saying than the doctors" pp12. "Listen more to what you have to say, some of the doctors don't just listen, is just flowing over their heads" pp13.<br>"Well, I get more information from a nurse than I would from a doctor pp12. They go about it in a different way, they discuss first what is wrong with you as where the doctors will tell you what is wrong with you" pp12<br>"Now and again. Very rarely, I am just talking to you like" pp13 | Quality of engagement varies among health professionals.<br><br>Engagement: Quality of information provision varies among health professionals. |                  |
| PE         | S&N      | Verbal  |   | "Nurse have more time for you than the doctors"  | Engagement: Quality time varies with health professionals.  |                  |

| RESPONDENT | CATEGORY | SERVICE USER WAYS (METHODS) OF COMMUNICATING WITH CARERS AND PROFESSIONALS. |   | SERVICE USERS' VIEWS/EXPERIENCES OF COMMUNICATION   |   |   |
|------------|----------|---|---|---|---|---|
|            |          | Verbal. comm  | Non-verbal or both  | Perceptions of communication with carers and professionals.   | Explicit/implicit interpretation.   | Others/ comments                            |
| PT         | S&C      | Verbally with carers  | "I think we should try and not use a lot of words but some very few words along with the pictures" pp21 | "I find that if they speak on a one-on-one. If you got more than one-on-one you have got no communication with them. If you have got like one-on-one is not too bad but if you got more than one-on-one then your brain can only take so much in at a time".<br>"I think we should try and not use a lot of words but some very few words along with the pictures" pp21 | Engagement: Strategy for effective engagement e.g. face-face<br><br>Information overload<br><br>Pictures as facilitators of communication | strategy<br><br>Barrier<br><br>Facilitators |
| PT         | S&D      | Verbal communications   |   | Participant expressed satisfaction regarding communication, however, advocated for the use of symbols and pictures to supplement spoken words. "I think we should try and not use a lot of words but some very few words along with the pictures" pp21  | Pictures to facilitate communication  | Facilitators                                |
| PT         | S&N      | Verbal  |   | You do get them on one-on-one but changes to medication pattern are a particular concern. "They alter your medication and your brain can only take in so much at a time Jerry, you know"  | Engagement: Pictures: overload, understanding. Information overload   | Barriers                                    |

| RESPONDENT | CATEGORY | SERVICE USER WAYS (METHODS) OF COMMUNICATING WITH CARERS AND PROFESSIONALS. |                    | SERVICE USERS' VIEWS/EXPERIENCES OF COMMUNICATION  |   |                  |
|------------|----------|---|--------------------|--|---|------------------|
|            |          | Verbal. comm  | Non-verbal or both | Perceptions of communication with carers and professionals.  | Explicit/implicit interpretation.   | Others/ comments |
| PG         | S&C      | All verbal  |                    | "He is the person who knows what I am going through, he does listen. I see sometimes other people are not bothered listening to me even though we have meetings up here" pp 27.<br>"Yes he agrees with what I want to do but I feel controlled for some reasons, I am not sitting waiting till Thursdays and then go to my work, sitting doing nothing, I want to work from Monday to Friday, I am not sitting about" pp25   | Engagement: Quality listening is dependent on the health professional<br><br>Apathy/empathy<br><br>Relating to employment   |                  |
| PG         | S&D      | All verbal  |                    | "Sometimes the doctors don't want anybody else, you feel like they have no time for you to speak to that is why you are holding things in, they don't want to listen, they are that busy but even if you say I want to sit and have a word they want you out of the door" pp27. "Sometimes looking away from you, there is no eye contact"pp27. "A little bit but they are not letting you know what they are thinking" pp27.<br>"I do but I think I do frighten them. The way I speak to them, you would listen either or you would not do that with me like, I would sit for nearly a day and won't let anybody out and lot of folks don't like it. They are really, really scared of me, that is the only way they can listen" pp27 | Engagement: Quality Time spent is dependent on the health professional: More time with nurses than doctors<br><br>Apathy/empathy<br><br>Behaviour as strategy for effecting engagement e.g. fears and intimidation. |                  |
| PG         | S&N      | Verbal  |                    | "Nurses have helped me when I was off for a week with my knee" pp27  | Caring/support.   |                  |

**Table 8. Summary of the emerging themes and sub-themes from the analysis**

| SERVICE USERS VIEWS/EXPERIENCES   | CARERS VIEWS/EXPERIENCES   |
|---|--|
| <b>1. Service user and carer views/experiences of communication with health and social care professionals.</b>  |  |
| Engagement;<br>Time; Listening; empathy; Understanding; information provision;<br>strategies; Fear/intimidation; humour; Involvement; duration/period of caring,<br>Impairments; Familiarity; Specialists professionals | Engagement eg Time; Listening; Knowledge/information needs;<br>Involvement eg Information sharing; Assertiveness; Specialist<br>professionals; Familiarity; Advocacy |
| <b>2. Service user and carer communication purposes/reasons with health and social care professionals</b>   |  |
| Health related eg, concealing/withholding of information, Medication errors,<br>Mix-match of information or messages, More involvement in information<br>sharing, Trust/Credibility of service user                     | Epilepsy related eg knowledge and information; More involvement;<br>Consistencies in Information sharing, need for<br>Specialist professionals.                      |
| <b>3. Barriers to communication with health and social care professionals</b>   |  |
| Stigma; Cognitive/memory impairments; Limited time; Information overload  | Knowledge; Limited time; Stigma; Non-involvement in information<br>sharing.  |
| <b>4.Means/methods of communication with health professionals</b>   |  |
| Mostly verbal means; Non-verbal means e.g. gestures, photographs/pictures,<br>patient passport.   | Verbal means (some carers also have disability)  |

| SERVICE USER VIEWS   | CARER VIEWS   |
|--|---|
| <b>1. Service user and carer view/experiences regarding their communication</b>  |   |
| Engagement; Listening; time; understanding; Style; Gender; self-caring; Understanding, e.g. pace, dialect, strategies eg pictures/photographs; empathy; Tension/controlling?; Gender; Familiarity/caring relationship; Knowledge and information; information overload | Engagement; Engage effectively with carer eg Listening; understanding; time; Knowledge; Empathy; Involvement; self-caring, life styles?; information overload; Impairment; duration/period of caring; Familiarity |
| <b>2. Communication needs and purposes between service user and carer</b>  |   |
| Unrelated to health management: Mostly related to social events and daily activities e.g. shopping, finances, etc; Self-caring; information regarding epilepsy and medication; independence; stigma  | Unrelated to health management: Mostly about social activities and events; Epilepsy and medication information, self-caring, Stigma   |
| <b>3. Barriers to communication between service users and carers</b>   |   |
| Multiple carers; Cognitive impairment; Time; Articulation; Gender; information overload  | Vocabulary; Cognitive impairment; Life styles; stigma; Limitations in alternative communication methods, care's learning disabilities   |
| <b>4. Means/methods of communication</b>   |   |
| Verbal; Non-verbal e.g. gestures, photographs/pictures; Fellow service user  | Verbal means; Non-verbal means, pictures and photographs  |

### 4.3 Analysis of the carer communication diaries

Four care workers who were conveniently sampled (see Chapter 3) completed the communication diaries for this study (two females and two males). They were offered the choice to choose a communication event/activity from each of three categories including; routine planning, domestic chores and health management. All events/activities were given equal weighting in terms of context and content (see Appendix 9). Entries were made for a total of five different activities comprising, shopping, laundry work, gardening, tidying up and health management (see Table 9 below). Preliminary analysis of the interview data and the emerging themes guided the design of the communication diaries, for example it informed the examples of activities provided in the accompanying guidance. The contents of the diaries were analysed thematically and reflect the four processes of familiarization, indexing, charting and interpretations.

First, familiarization with the content of the diaries as a whole occurred. This involved reading through the diaries several times to gain a thorough understanding of the whole data and context (Astedt-Kurki and Isola, 2001; Gillham, 2000). Second, the entries of each activity/event were read again, at this time highlighting, substantive statements, emergent or recurrent themes (Gillham, 2000). Third, charts were then drawn for each participant and summary of the emergent themes from each of the activities sorted under four categories: methods/means of communication, strategies of communication with service user; the aspects of communication that help in the activity, or hinder the activity (communication barriers) and any learning experience drawn from doing the activity for future reference (recommendations for the future).

**Table 9. Charted carer communication diary showing categories of themes and sub-themes**

| Care-worker | Activity/ events          | Communication methods/ How ideas were communicated.  | What kind of communication helps or was good about this activity?  | What aspects of communication failed to work well? (barriers to communication)   | Learning experiences (recommendations)  |
|-------------|---------------------------|--|--|--|---|
| DMW         | Preparing a Shopping list | Verbal...‘approached me and asked for help with task. ‘we use verbal communication and writing skills; Gestures: ‘She was able to point out gifts from the shelves ‘pp5 ‘Sometimes we use our hands to illustrate a point’ | One-on-one communication with service user: ‘we also went out to a local café’ for a bit of uninterrupted planning time’pp5. This also, relates to communication environment   | lack of vocabulary: ‘Sometimes she found it hard to communicate ideas she had but could not verbalise easily’pp6   | Guidance and empowerment and choices; Pictures: ‘catalogues and brochure; Environment:’ we also went out to a local café’ for a bit of uninterrupted planning time’pp5  |
|             | Laundry work              | Verbal communication   | Time, one-on-one: ‘I waited until I and her had time alone in the dining room’, pp7 ‘I made sure that she is focused by summarising before we finish our chat’ ; Planning e.g. rota: She knew by the rota that it was her turn to use the washing machine’ pp7 | Lack of concentration, lack of time management, cognitive impairments. ‘Had difficulty in managing her own time and was easily distracted from her chores’pp7. I have to remind her several times and I was aware I might have been almost nagging which makes her less likely to complete her job’pp8 | More time for service user to work on her own pace pp8. Simplify tasks: ‘I have offered support with some of the tasks’pp8; Planning e.g. rota: She knew by the rota that it was her turn to use the washing machine’ pp7 |
|             | Health management         | Verbal communication   | One-on-one time. ‘I found time to be alone with her to discuss things in privacy’ pp9  | Anxiety regarding lack of support. ‘she was concerned she might have to go there without support’pp9   | Reassurances to service user; Support with appointments: ‘I found time to be alone with her to discuss this in privacy’ pp9   |
| DRJ         | Shopping                  | Verbal   | Clear and simple words, choices, enough time   |  | Allow enough time, empowerment.   |

| <b>Care-worker</b> | <b>Activity/ events</b> | <b>Communication methods/ How ideas were communicated.</b> | <b>What kind of communication helps or was good about this activity (Engagements).</b> | <b>What aspects of communication failed to work well? (Barriers to communication).</b> | <b>Learning experiences (recommendations).</b>                |
|--------------------|-------------------------|--|--|--|---|
|                    | Laundry work            | verbal and non-verbal e.g. gestures                        | Short sentences with gestures, physical demonstration.                                 |  | keeping information short and using key words                 |
|                    | Health management       | Verbal with prompts supervision                            | Guidance/support, prompts 'Observe...'taking her tablets and inhaler' pp               | Enough time and space for service user to work at her own pace                         | Service user may need some form of prompts to undertake tasks |
| DGS                | Shopping list           |  | Time and reassurance. 'reminding... to take his time and thinks things through'        | Limited time, rush in undertaking tasks.   | Empowerment of service user                                   |
|                    | Ironing                 |  | Involvement through communication and working together with service user.              | Disability related   | Physical impairment affects performance with task.            |
|                    | Health management       |  | Discussion regarding healthy life.   |  |   |
| DBM                | Gardenin g              | Verbal methods   | Reassurance and praise   | Lack of motivation, lack of assistance   | Identify individual needs<br>Build a working relationship     |
|                    | Tidying up work shop    | Verbal communication                                       | Motivation, praise and appreciation  | Lack of assistance   | Body language<br>Consistency                                  |
|                    | Health management       | Verbal communication                                       | Listening and giving reassurance, Advice to seek appropriate supports                  | Taking away responsibility (independence).   | No entries  |



Four, mapping and interpretation occurred by looking across each participant entries, synthesising and interpretations. Cross comparisons with other participants' entries were undertaken to further highlight similarities and differences. The data were then interpreted as a whole. Finally, the emerging findings were sorted into categories of main themes and sub-themes as summarized below.

## 1. Methods of communication

Verbal:

*"We used verbal communication and writing skills" Diary MW*

Non-verbal e.g. gestures, pictures:

*"She is able to point out gifts from the shelves" Diary MW*

*"Body language and tone of voice is a strong indicator concerning.....well-being" Diary BM*

## 2. Strategies and styles of communication

One-on-one sessions:

*"I waited until I and her had time alone in the dining room and we talked about what was needed to be done" Diary MW.*

*"I found time to be alone with her to discuss this in privacy" Diary MW*

Identify a suitable environment:

*"We also went out to a local café' for a bit of uninterrupted planning time" Diary MW*

Planning:

*"She knew by rota that it was her turn to use the washing machine" Diary MW*

Empowerment:

*"Just to let him do as much for himself as he can" Diary GS*

Sufficient time to complete task at own pace:

*"...Likes being left to complete things in her own time" Diary MW*

*"...Trying not to rush him" Diary GS*

*"By keeping a calm manner and doing the shopping at service user pace" Diary AJ*

*"I might start earlier to give her more time" Diary MW*

### 3. Facilitating factors of communication

Reinforcements:

*"Sometimes the conversation went onto other matters but I made sure that she is focused by summarizing before we finish our chat" Diary MW*

Provision of choices to communicate:

*".....catalogue and brochures could be used" Diary MW*

Accessible language:

*"Simple words using clear and understood language" Diary AJ*

Reassurance:

*"Checking with....that she was ok to carry on with the task and showing appreciation" Care Diary BM*

*"Reminding her to take her time and think things through" Diary GS*

### 4. Communication purposes and needs

Guidance /supervision relating to health management:

*"Observe....to take her tablets" Diary AJ*

*"Observe...taking her tablets and inhaler" Diary AJ*

Self-management:

*"....watches what she eats and also like to keep her weight under control" Diary GS*

*"Knows when to take her medication" Diary AJ*

*"...Had a positive attitude towards her health care and was quite willing for me to arrange an appointment at the clinic" Diary MW*

*"...Had a pretty good idea of what to buy for her relatives and just guidance regarding cost, once she felt confident in her choices she was empowered and pleased with her list" Diary MW*

## 5. Barriers/obstacles to communication

Physical/cognitive impairments:

*" Sometimes she found it hard to communicate ideas she had but could not verbalised easily" Diary MW*

*"I have to remind her several time and I was aware I might have been nagging which makes her less likely to complete her job" Diary MW*

*"Had difficulty in managing her own time and was easily distracted from her chores" Diary MW*

Anxiety/fear:

*"She was concerned she might have to go to the clinic without support" "Once she understood staff would support her in this activity she was content to go ahead" Diary MW*

### 4.3.1. Conclusion regarding findings from diaries

Carers' reported methods of communication with service users were mostly verbal reflecting the interview data. To a very limited extent, non-verbal methods such as gestures, pictures and photographs were reported. However, it remains unclear how much of the non-verbal forms of communication were unreported or unrecognised by carers. In addition, a wide range of communication strategies and styles were reported or suggested for consideration when engaging with service users. Also, carers reflected on factors that have facilitated the activities or could facilitate future activities or events, when engaging in communication with the service users. Furthermore, communication barriers identified were largely similar to what was reported in the interviews.

Moreover, activities or events that were identified by carers were largely unrelated to health management but were mostly centred on activities of living. However, those carers who reported events relating to health issues did so, on a superficial level. This is a reflection of carers' limitations and non-involvement in health management with service users. Overall, it was apparent that the findings from the communication diaries largely endorses or illuminates what emerged from interview data.

## Chapter 5: Findings

### *5.1 Introduction*

This chapter will focus on the findings that emerged from this study. It does this first, by highlighting the demographic characteristics of the study participants and second, by presenting the overall findings (both interview and diary data).

### *5.2 Participants' characteristics*

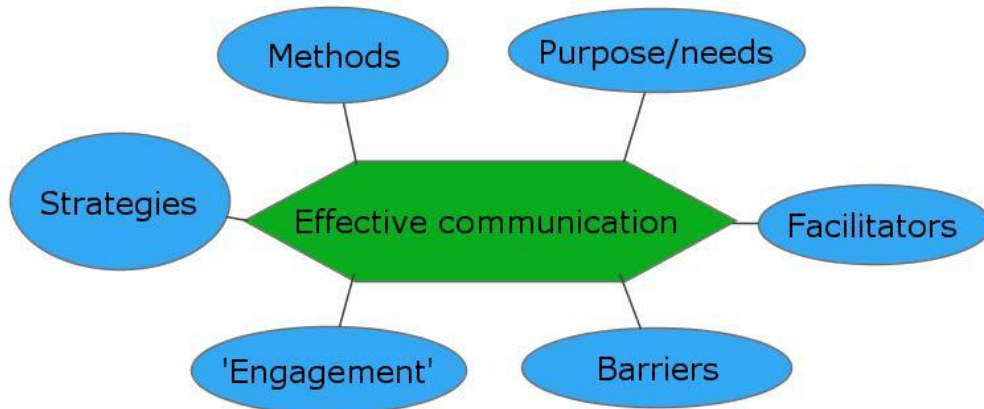
Pairs of 15 service users and their carers were recruited for this study. Data were collected from 28 participants. Two carers were excluded from the study (one care worker did not meet the inclusion criteria and the other declined to participate in the study). All participants but two carers consented for the interviews to be taped. However, the researcher was permitted to keep written notes of the interviews. Two carer participants have learning disabilities but not epilepsy and one carer participant also has epilepsy but not learning disabilities. In terms of demographic characteristics 61% of the participants are females (17) and 39% (11) are males (see Appendix 10).

Overall, the nature of epilepsy control in the majority of the service users was reported as good by service users and carers. However, in a few cases, the epilepsy control was reported to be poor. Participants were given the choice to decide the location for the interview for example, at their own homes, day centres, the GP surgeries or at the university if they so wish. The majority 79% (22) preferred and were interviewed at home and the others 21% (6) at the GP Surgery and Day-care centres (Appendix 10). Regarding service user/carer relationships, 11 were care workers with only four family carers. The types of support provided for service users was mainly based on activities of living with very little or no involvement in health management.

### 5.3 Findings from the interviews and diaries

People with learning disabilities as service users in this study have potentially powerful insight regarding their communication with carers and health care professionals. Although service users' and carers' experiences of communication regarding epilepsy and related issues are multiple and different, active engagement in communication was widely viewed by service users and carers as a strong predictor of effective communication. In this chapter the overall findings derived from both the interviews and the diaries will be presented. In presenting the findings, the main themes are introduced. Following this, the sub-themes that explore the service users' and carers' diverse views and experiences of communication with each other and also their perspectives and experiences regarding health and social care professionals' communication are reported. The presentation begins with a brief introduction of the main themes followed by the sub-themes, accompanied by quotation/s in italics and enclosed in quotation marks ("") to illustrate the theme. It was apparent that some words/terms were deeply rooted in the local dialect. Therefore, substituted words are put in square brackets [ ] to clarify the meaning and context. Also broken lines (.....) are used to denote a pause or be indicative of portions of sentence or statements that are not relevant to the phenomenon described. Themes that emerged from the analysis (see Table 8) were synthesised and sorted into six main themes as the key components of effective communication (see Figure III below).

**Figure III. Main themes of the findings**



*5.3.1 Engaging with carers and health care professionals*

This theme described the active transaction of communication involving service users and their carers; and also the views and experiences of service users and carers regarding their communication encounters with health care professionals, in particular, with respect to the exchange of information.

**Figure IV. Theme and sub-themes of 'engagement'**



There are ranges of views and experiences regarding how service users and carers engage in communication and also their views regarding health care professionals' communication. These views are

shown as sub-themes in the Figure IV above and contained both positive and negative experiences.

### *Listening and understanding*

A positive observation was that service users and their carers are able to transact communication effectively with each other regarding listening and the understanding of information as demonstrated below:

*"She listens to me, she will sit down, listen and she will ask me questions" Service user PI*

*"Is easy, even though she comes from [location] and I come from different part of the world we do understand each other" Service user PE*

*"He is the person who knows what I am going through, he does listen. I see that sometimes other people are not bothered listening to me even though we have meetings up here" Service user PG*

And also, service users are able to disengage from communication and decide when to listen and what not to listen to:

*"She will definitely let you know what she is talking about, if it is something she does not want to hear is quite difficult to get through to her because she thinks I am just trying to 'have a go' at her rather than help her. She just listens to what she wants to hear" Family carer PB*

However, service users in this study have expressed specific concerns relating to engaging with multiple care workers. They described their experiences of interacting with multiple care workers as confusing and thus, impacting on their understanding:

*".....[care worker] does listen to me but then it is when you have more than one person dealing with different medications you get so confused Jerry, you know? You get like one person dealing with your*



*morning ones then you get one person dealing with your lunch time ones and another one dealing with your tea time ones then you get another guy dealing with your bedtime. So is not the proper pattern you know. I get confused because sometimes my brain tells me one thing" Service user PT*

Moreover, service users' and carers' views and experiences regarding listening and understanding with health care professionals are wide ranging. Although carers, in particular, have expressed satisfaction regarding communication with health care professionals, this was very limited:

*"They understand and listen most of the time if not I will stop them and tell them to say that again I have not understood you or tell me that again" Care worker PW*

However, overall service users' and carers' views and experiences of communication with health care professionals regarding listening and understandings are primarily negative. Both service users and carers have persistently reported that they are not being listened to by health care professionals. However, this was reported to vary with the individual's health care professional and also with the professional discipline:

*"Nurses are more listening than the doctors; they are more 'geared up' [listening] to what you are saying than the doctors. Some of the doctors don't just listen, is just flowing over their heads" Service user PE*

*"I think the doctor was not probably listening to me. There was one doctor I think last week I have been on medication for my depression and one doctor tries to reduce it, but on Friday I have to go past and get it put back to normal" Service user PC*

*".....we used to have one doctor called [name] he used to listen and listen and listen. In the majority of times they [doctors] listen to you*

*so far and chuck you out of the door with a piece of paper and say you get this and get that” Family carer PS*

*“.....they [doctors] only listen to what they want to listen and that is the end of story” Family carer PS*

In addition, service users and carers have expressed other concerns but these *only* apply to their engagement with health care professionals.

### *Quality time*

A recurrent concern that was expressed by both service users and their carers related to the quality of time engaged with health care professionals. Service users and carers would value more time to enable them to engage effectively with the health carer professionals. Below are excerpts of what was reported:

*“Sometimes the doctors don’t just want anybody else; you feel like they have no time for you to speak to, that is why you are holding things in. They don’t want to listen, they are that busy, but even if you say I want to sit and have a word they want you out of the door”  
Service user PG*

*“I did feel that I went down to see the doctor, I felt she was like quick out of the door and I spoke with [nurse] and he was totally different”  
Care worker PQ*

*“I will say just maybe sometimes the doctors should listen a bit more but it boils down to how much time they have for each patient. Sometimes you feel especially with someone with learning disabilities if you are talking to them sometimes it takes longer than these ten minutes of allocation. And sometimes the person does not communicate that well and you find that it takes a bit longer and you feel a bit rushed” Care worker PO*

### *Quality of information provision*

Another persistently reported concern that was expressed by service users related to the quality of information received from health care professionals. Service users reported that the quantity and quality of information obtained from health care professionals was limited. However, this was also reported to vary among individuals and also with the health care professional groups:

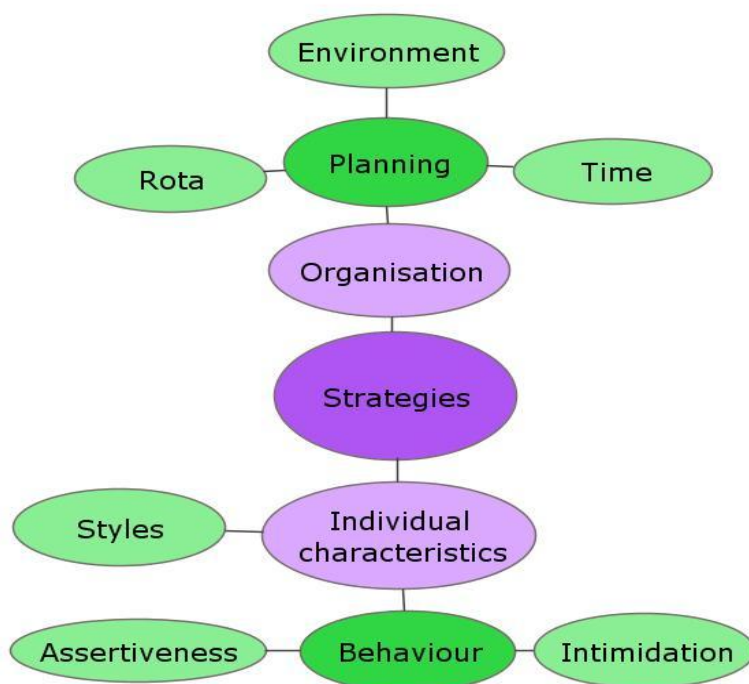
*".....I get more information from a nurse than I would from a doctor, they go about it in a different way, they discuss first what is wrong with you as the doctors will tell you what is wrong with you" Service user PE*

*"Doctors are funny people, nurses get down to the 'nitty gritty' and help you, where doctors don't" Service user PP*

### *5.3.2 Strategies of communication*

The theme strategies of communication related to how service users and carers describe certain approaches they adopt to effect communication with each other and also with health care professionals.

**Figure V. Theme and sub-themes of strategies**



Service users and carers reported ranges of strategies of communication which they used or could be used in order to make communication more effective. These communication strategies are shown in Figure IV above and broadly reflect the characteristics of the individual communication partners. They include individuals' use of various styles when communicating with others; the reflective use of certain behaviours to effect communication; and the requirement for organisation and planning such as timing and identification of a suitable environment.

#### *Individual characteristics*

Both service users and carers reported their awareness of when and how they adopt various styles as strategies to communicate with each other:

*"If I am talking to my friends is my usual "banter" but usually softer when talking to her [carer]" Service user PE*

*"I get confused about sometimes and she [carer] explains it in a different way and I will understand" Service user PN*

*"We try to make it as adult as possible but we have also got the level of understanding to try and clarify things or simplify things as much as we can. It is always a difficult one she is an adult but there is a learning disability and at times we need to sort of simplify things" Care worker PL*

Furthermore, service users and carers reported that they adopted certain behavioural strategies, including intimidation as means of communication to ensure they are listened to; and thus to effect communication with their health care professionals:

*".....I do but I think I do frighten them. The way I speak to them; you would listen either or you would not do that with me like, I would sit here for nearly a day and won't let anybody out and a lot of folks don't like it. They are really, really scared of me, that is the only way they can listen" Service user PG*

*"If she [service user] is not getting her way, certainly in the past she has used seizures and she can fake them fairly well" Care worker PL*

*"If you appear to be assertive and a no nonsense sort of person you get listened to; but if you are subservient and look like you will accept a lesser service then that is what you are given" Care worker PW*

### *Organisation*

In addition to the above strategies, the carer communication diaries have also yielded ranges of other communication strategies which are employed by carers to communicate with service users. However, entries in the carer communication diaries only related to the daily communication of service users and carers except when it related to health management. Planning was widely viewed by carers as an important strategy for any communication event or session with

service users. Planning involved ranges of activities as suggested by carers.

Firstly, carers found it useful to prepare a rota so that service users become familiar with the routines and are made aware of what needs to be done and at what time. This appears to facilitate communication:

*"She knew by the rota that it was her turn to use the washing machine" Diary MW*

Secondly, carers forwarded that identifying a suitable communication environment is an essential component of any successful communication. When a conducive environment is selected that is free from any distraction it may promote concentration and thus enhance communication with the service user:

*"We also went out to a local café' for a bit of uninterrupted planning time" Diary MW*

Thirdly, it was widely reported by carers that service users may work slowly or communicate at a slow pace. Therefore, service users may require sufficient time to work at their own pace and this should be taken into consideration when communicating with service users:

*"I might start earlier to give her more time" Diary MW*

*"..... [Service user] likes being left to complete things in her own time" Diary MW*

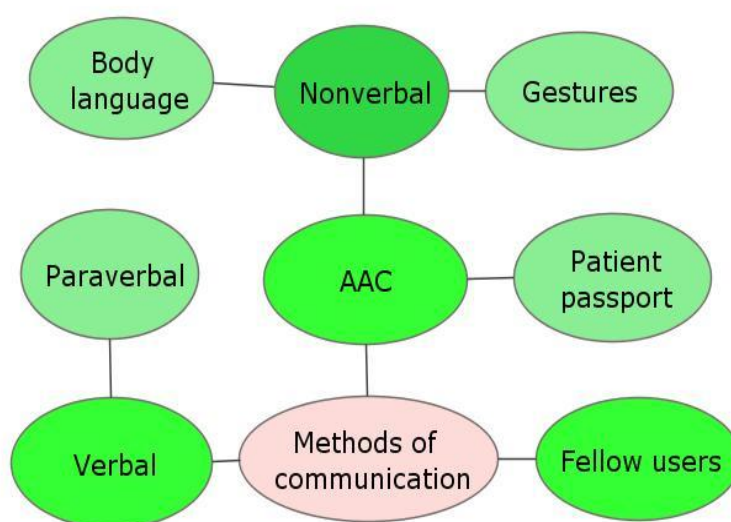
*"....Trying not to rush her" Diary GS*

*"By keeping a calm manner and doing the shopping at [Service user] pace" Diary AJ*

### 5.3.3 Methods/means of communication

This theme related to methods and means employed by service users and carers when communicating with each other and also with health care professionals

**Figure VI. Theme and sub-themes of methods of communication**



Service users and carers have reported ranges of methods and means of communication. These methods range from verbal and paraverbal modes of communication and other augmentative and alternative communication methods such as gestures, body language and 'patient passport' (see Figure VI above).

#### *Communication media*

Overall, the dominance of verbal methods over non-verbal means was well reported. Service users and carers relied heavily on verbal communication as their main method of communication:

*"I just talk to her" Service user PI*

*".....Is words she understands" Service user PE*

*"Me and [Carer] can really approach one another and talk to one another" Service user PC*

*".....I don't know any sign language" Service user PR*

*"....all words by voice. He is eloquent and he will just hold a normal conversation the same way like anybody else" Care worker PH*

*".....is just by voice, I have to be careful with how I use my voice and try and communicate" Care worker PD*

*"Just by voice, we don't need to use signs language we just talk or phone" Family carer PB*

*"The usual (daily) conversation we don't tend to use signs and pictures, we have not found the need for them" Care worker PU*

*An isolated case was the use of paraverbal communication methods by a carer: "Hopefully in an adult basis and as much as possible she understands the verbal communication which helps a lot" Care worker PL*

Service users in particular, are aware of non-verbal forms of communication such as gestures:

*"...I use my hands such as moving my hands you know" Service user PI*

*".....when you use your hands and whatever" Service user PE*

*"We used verbal communication and writing skills" Care DMW*

However, reported uses of non-verbal communication methods by carers were very limited:

*"I gesture with my hands sometimes" Family carer PF*

*"She is able to point out gifts from the shelves" Carer DMW*



*"Body language and tone of voice is a strong indicator concerning.....well being" Carer DBM*

Although carers reported their awareness of some non-verbal methods of communication such as photographs and pictures, they are very rarely used on daily communication except when it relates to domestic chores:

*"You can see in the kitchen we have used little symbols pictures and things like that just to clarify some matters but normally she can understand the written and verbal so it makes it easier for communication" Care worker PL*

*"There will be things such as an action plan we try to use during a review which she agrees to, so what is going to happen so you get instead of words you get pictures" Care worker PU*

Moreover, however rare, carers cited the use of the 'patient passport' during consultations, in particular for health professionals who were not familiar with the service user:

*"There is a form going to the doctors in use which came from the community learning disability team for somebody or GP who is not familiar with her can have a look" Care worker PU*

An additional method although less recurrent, service users reported their dependence on fellow service users as a way of meeting their daily communication needs:

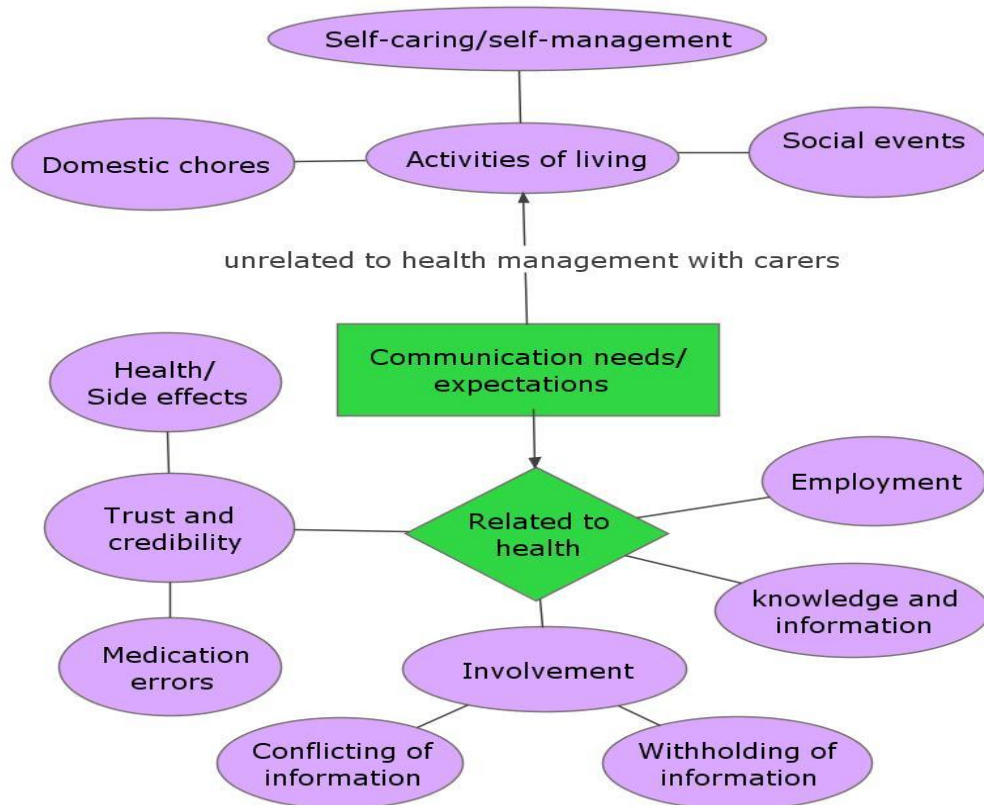
*"...I have a friend, his name is [name] he translates me to some folk. He comes here to visit me" Service user PI*

#### *5.3.4 Communication needs and expectations*

This theme explores service users' purposes and needs of communication with their carers and health care professionals. It discusses what service users and carers talk about, what concerns

them in their daily communication with their carers and health professionals; and also, carers' communication requirements of health and social care professionals.

**Figure VII. Theme and sub-themes of communication needs and expectations**



The findings revealed that service users in this study are very selective and are well aware of their communication needs with carers and health care professionals as shown in Figure VII above. For example, service users know what they want to talk about and who they want to talk to:

*"There is a stumbling block because is happening right now, she is coming to me with her problems but she is not sharing the same problems with her GP, she is not sharing the same problems with the Psychiatric nurse, but I feel uncomfortable going to the GP because I will be crossing boundaries here and I rely on her to convey appropriate information" Care worker PD*

### *Service users' communication with carers*

Although service users' purposes for, and needs of, communication with their carers are wide ranging, they are largely unrelated to health management but primarily based on activities of living:

*"If I have anything I will talk to her but not personal things. My hair, my money and what happens in the building during the week but not personal things e.g. my relationship" Service user PI*

*".....everyday sort of things; politics or whatever and the news papers, we have booked appointments to go and see McDonald brothers" Service user PE*

*"....well, I am away to get my hair done at 12:00 noon. I will get my hair done" Service user PX*

*"Just normal things we do, daily stuff, TV, books etc" Family carer PF*

*"He likes fishing and I like fishing so we talk a lot about that and we sometimes go fishing. He also likes aircrafts so just the day to day things" Care worker PH*

*"He always got questions for me [carer] daily life, his family, work etc" Carer PJ*

*"Just everything, his family, his kids, ex-wife, money, council tax, shopping etc" Care worker PQ*

*"Just what she is been doing with her time at the day services. I try to find out what she has been up to at the weekend but she does not always tell me because sometimes she gets into trouble so she does not always like to tell me" Care worker PAb*

*"Just household and domestic things for example her pets, she has a dog and two cats and her conversation is mostly about them and about the Day-centre activities" Family carer PB*

Although extracts from the carer communication diaries suggested that carers provide some forms of guidance and support regarding health management, this was very limited:

*"Observe her to take her tablets" Carer DPJ*

*"Observe her taking her tablets and inhaler" Carer DAJ*

However, overall service users and carers appeared to have very limited communication regarding epilepsy and related issues:

*".....we don't speak about it at all" Service user PG*

*"As far as his epilepsy is concerned, he very rarely broached it as a subject unless he actually had a seizure and sometimes he will tell us that he had a seizure" Care worker PH*

Moreover, a carer reported that it is unpleasant to talk about epilepsy because it traumatises the service users and above all it reminds her of painful experiences in past of which the service user cannot remember, so it is unnecessary to talk about them:

*"She took an 'epileptic fit' in the [local] restaurant. She had a terrible 'fit' there they could not be any nicer but she does not remember, afterwards she does not remember going into them and prior to them so we don't discuss that too much. I feel sorry for her but I don't kind of dwell on it because there is no point, she got no idea of what we are talking about" Family carer PB*

There are ranges of views attributed to this limited communication regarding health management by service users and carers. These include:

Firstly, to some extent, it was widely recognised by both service users and carers that service users are self-managing and thus carers have limited input regarding health management:

*"...he is self-medicating and once again I think because he sees himself as so able he will not allow me anything to do with his medication" Care worker PH*

*".....[service user] kind of look after that herself, the only time it comes up is maybe when she is forgotten to put in her prescription to get a repeat medication and is the case I have to run and get emergency prescription but she gets a lot herself really, and she is good at taking her medication as far as I am aware" Care worker PAb*

*"She is well aware of the medication she has to take, she keeps a close eye on that and take a keen interest, if there is a strange tablet she will ask she will not just take it" Care worker PW*

*".....myself I don't want to put so much on the carer really, because if you put so much on the carer you will start depending on the carer which to me is wrong because they have got their own life, you have got yours and you can't always stick onto them" Service user PP*

These views were also reflected in the carer communication diaries:

*"....She watches what she eats and also like to keep her weight under control" Diary GS*

*"....had a positive attitude towards her health care and was quite willing for me to arrange an appointment at the clinic" Diary MW*

*"..... [Service user] knows when to take her medication" Diary AJ*

Secondly, health management was regarded by service users as a role reserved for health care professionals and therefore service users do not think carers should necessarily be involved in health related issues:

*"I don't think she knows a lot, is up to her to keep an eye on but if you don't take your tablets is your fault because she is not here for*

*that she is not here as an epilepsy nurse she is just a carer and there is a difference between a carer and a nurse" Service user PP*

Thirdly, carers in particular expressed their wish to communicate but appeared to be constrained by their lack of knowledge regarding epilepsy and medication:

*".....a gap in knowledge because I don't know obviously enough about as much as I should because I work with her and more knowledge for what to look out for, just general knowledge of epilepsy would be ideal" Care worker PAb*

*"I understand there are training programmes but I have not been yet" Care worker PAb*

*"She would like to know more about it as I would like. That is what she needs to do, to learn something about epileptic fits" Service user PE*

*"I asked and I was given a DVD video for a shot and return it but it does not teach me anything. I would like to know more about epilepsy of what to do if he takes a 'turn' [seizures]. What I need is somebody to come up and sit down with me and tell me more about epilepsy is all I need but everybody is busy and I am not the pushy type of person" Family carer PF*

### *Service users' and carers' communication with health professionals*

However, overall, service users' and carers' communication purposes and needs for health and social care professionals are based on wide ranges of health related issues. In particular, service users have consistently expressed concerns regarding the lack of involvement regarding medication:

*"The doctors will tell you, take your tablets and that is it, whereas people like [nurse] will help you, talk to you about it, sit down face-to-face whereas doctors will want you out of the door"* Service user PP

Similarly, carers have also expressed their wishes to be more involved in decision-making regarding service users and to be able to advocate for service users when necessary:

*"I would just like to be able to talk a lot more about her so that if I am worried I can discuss it with them and between us we can put it right hopefully"* Family carer PB

*".....I tried to change her appointment because she had no time to do it or something and I phoned the reception and say could she change it from this time to that and they said they are sorry they could not do it because it was confidential and that was just stupid because it has nothing to do with medicine. She was just asking to change but I suppose maybe they do get some 'nutters' who would do it for fun but I am her mum. Is stupid because they knew I am her mum they can identify the two of us together. I think if you know the way she is they should be a bit more forthcoming because she can't always relay it to me you know"* Family carer PB

Moreover, other concerns that were repeatedly expressed by service users related to health professionals withholding or concealing of information from service users. Service users would value more involvement regarding changes to medications to be openly and honestly discussed with them:

*"I find it very difficult sometimes you have a very bad back problem. I used to get pain killers for bad back ache but they have taken them out these pills that I used to, they don't have any side effects with my medications but they have taken them off"* Service user PT

*"There was one doctor I think last week I have been on medication for my depression and one doctor tries to reduce it because I have not been getting the truth that ok... [doctors] have reduced it and all that*

*my antidepressant but on Friday I have to go past and get it put back to normal" Service user PC*

Furthermore, other communication needs related to conflicting information from health professionals and the need for consistency in information provision:

*"They have put a stop to my other tablets that I used to take but I don't know why, I think the...[nurse] said the learning disabilities team agreed on that but when I spoke with my Mum, my Mum said I was best taking two at lunch time instead of the one" Service user PT*

This view was also shared by carers' who advocated for their involvements in multidisciplinary team meetings to ensure that information is consistently shared:

*"There is a stumbling block because is happening right now, she is coming to me with her problems but she not sharing the same problems with her GP, she not sharing the same problem with the Psychiatric nurse, but I feel uncomfortable going to the GP because I will be crossing boundaries here and I rely on her to convey appropriate information" Care worker PD*

*"But sometimes I just wish that there was a bit more communication with the support workers from the doctors and nurses but then everybody is busy" Care worker PQ*

Nevertheless, persistent concerns were expressed by both service users and carers regarding the lack of trust relating to medication. Service users in particular have expressed serious misgivings regarding their medication. Views on this were triggered off following medication errors. This led to service users questioning whether their prescribed medication was not in fact, wrong:

*"Medication is funny, there are so many things going on with my medication. For instance, the doctors got mixed up between my medication and my brother's medications, how is that? I try to understand whether I take different, medications" Service user PP*



*"I have been to the hospital here for once I don't know when, when I was four years but they did not give me the right medicine. This is what I cannot understand they have all your notes there and everything but give you the wrong medicine sometimes"* Service user PM

This view regarding errors in medication was supported by a carer:

*"He asked me a few months ago to double check his tablets because he felt the tablets were wrong and I did and the tablets were definitely wrong and we both went down to the doctors to get everything sorted out"* Care worker PQ

However, service users also reported that they are not being trusted by health care professionals especially when reporting health issues and their experiences with medications and side effects:

*"I am finding that I am sweating a lot because of the dizziness which I get angry because trying to explain to the doctors, sometimes when you are telling them you wonder if they believe you, it makes me cross sometimes. But is actually, you are going through it and they are just sitting on the chair and you wonder if they are taking it all in"* Service user PP

Another factor reported as central to service user communication with health care professionals related to goals and expectations. Service user's reasons for communication may be completely different from what the health professionals want to talk about. These differences in expectations may lead to break down in communication. For example, whilst the health professional may be interested in the management of epilepsy, the service user goal of communication with the health professional was all about accessing a driving license that would open up job opportunities, which he felt was being denied by health professionals. Thus, his communication encounter with health professionals was always dominated by employment issues and a need to obtain a driving license as reported below:

*"I want to get back driving; it does put pressure on me because you can't get a job because you need your license. Half of the jobs I have seen needs a clean driving license and so I cannot apply for it"*  
Service user PG

Furthermore, this service user recognised that having been denied his communication need in relation to driving and employment, a build up of anxiety with detrimental effect on his epilepsy is a possible consequence:

*"I want to get some more jobs but I am being held back. I want to get out in the morning, go to work and come home but not just sitting about. No transport, no driving licence and all that. If it builds up it may affect my epilepsy and I don't want to do that"* Service user PG

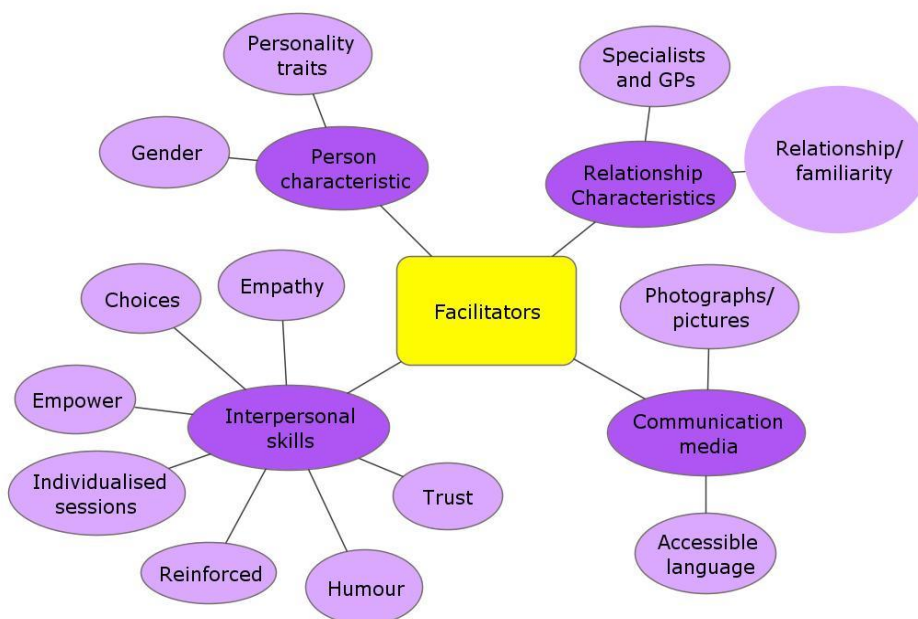
This observation was also reflected in the interview with the service user's carer, who reported that the service user is reluctant to discuss epilepsy except when it affects his opportunities to participate in his desired roles for example driving and employment:

*"He hates his epilepsy; of course it is holding him back for quite a few things so he does not really speak about it. The only time he will ever speak about it is when it comes up to looking for work and he will then go on about it. He is tied down with the kind of work he can do because he cannot get a driving license. He has a license but it is taken away from him during the epilepsy that is one of the times he will speak about it if work comes into the equation"* Care worker PH

### *5.3.5 Facilitating factors of and barriers to communication.*

This theme relates to factors that emerged or were reported by service users and carers which influenced their communication. These factors are either facilitators of, or barriers to, communication or both. Some of the factors identified here also included extracts from the carer communication diary. However, these extracts are only applicable to carers and service users' communication.

**Figure VIII. Theme and sub-themes of facilitating factors**



Service users and carers have reported wide ranges of factors which appeared to facilitate their communication with each other and also with health care professionals. Factors that were reported to facilitate communication largely related to; relationship characteristics, the individual's interpersonal skills, the media in which the communication is exchanged, the person or individual characteristics such as gender and the duration of the caring relationship or familiarity with the health care professionals as shown in Figure VIII above.

### *Relationship characteristics*

This theme reflects how the development of professional relationships and familiarity can influence the outcomes of communication. Generally, both service users and carers have consistently reported that the length of time or the duration of caring are facilitating factors for their communication. It enables them to establish familiarity and professional relationships with each other:

*".....25years we have been married, we must be able to communicate" Service user PR*

*"I have known [Service user] for over 20years, so I have learnt over this time the depth of her understanding and the level of her*

*vocabulary so I know which words she understands. So is quite easy for me to communicate with her" Care worker PW*

*"Well if it is my own doctor..... [I am able to communicate] but with different doctors is so so" Service user PR*

*".....it is absolutely vital to have doctors and nurses who know her [service user] well" Care worker PU*

*"Sometimes they don't understand me but sometimes [carers] do understand. I have been here since April so is quite a while now so I just understand them now" Service user PV*

The existence of family 'bonds' were viewed by both service users and carers as factors that facilitate familiarity and thus, enhance communication:

*"Me and my daughter we get on fine there is no mum and daughter frictions between us at all. We have our 'snappy' moment obviously, sometimes she gets on my nerves and sometimes I get on hers but there is nothing wild. We will never be on Jeremy Kyle show" Family carer PB*

*"I don't want to talk to [carer] I talk to my mum instead, she phone here all the time" Service user PAA*

However, other factors were also reported to facilitate services users' and carers' communication with health care professionals. Views on these related to specialised service provision. Both service users and carers associated specialist learning disabilities professionals and GPs who have interests in learning disabilities as good communicators compared with professionals in the general hospitals:

*"...[doctors] talk to me fine. The doctors at the surgery [learning disabilities practice] understand" Service user PI*

*"The doctors and nurses at the surgery are really good" Carer PJ*

*"I find that most of the GPs are very good" Care worker PL*

*"I think is different when you go into the hospital situation and they treat them very much child-like and speak to the carer rather than the person" Care worker PL*

### *Communication media*

This theme demonstrates the influence of certain communication modes and media as facilitators of communication. Although less recurrent, service users have advocated for the use of pictures and photographs to supplement spoken words as it may facilitate communication:

*"I think we should try and not use a lot of words but some very few words along with the pictures" Service user PT*

*"If we use pictures like these [pictures] I think it will help because it will give you an idea who is ready, talking, you would find it a lot easier to talk and to listen you know" Service user PT*

Also, carers emphasise that for communication to be effective, it needs to be accessible and understandable. Carers have reported their awareness of the vocabulary needs of the service users and the need to use accessible language and simple words when communicating with service users:

*"I think being nice and friendly and relax as well and get rid of the big words, I think not just for the person with learning disabilities I think we should learn to speak" Care worker PL*

This view was also reflected in the carer communication diaries:

*"Simple words using clear and understood language" Diary AJ*

### *Interpersonal skills*

Furthermore, carers have reported or suggested other ranges of elements which may facilitate communication with service users in the diaries. For example, extracts from the carer diaries suggested that communication may be more spontaneous when service users are provided with choices as this may facilitate communication:

*".....catalogue and brochures could be used" Diary MW*

In addition, communication may be facilitated when the message is reinforced by ensuring that it is understood:

*"Sometimes the conversation went on to other matters but I made sure that she is focused by summarizing before we finish our chat" Diary MW*

Moreover, service users' empowerment was consistently highlighted in the communication diaries. Carers held the views that when the service user feels empowered it may promote communication:

*"Just to let him do as much for himself as he can" Diary GS*

*"....[Service user] had a pretty good idea of what to buy for her relatives and just guidance regarding cost, once she felt confident in her choices she was empowered and pleased with her list" Diary MW*

*Checking with [service user] that she was ok to carry on with the task and showing appreciation" Care Diary BM*

Nevertheless, a more recurrent view shared by both service users and carers was that communication may be facilitated when it is considered on an individual basis:

*"I find that if they speak on a one-on-one, if you have got more than one-on-one you have got no communication with them. If you have got like one-on-one is not too bad but if you have got more than one-on-one then your brain can only take so much in at a time" Service user PT*

This view was also supported by extracts from the carer communication diary:

*"I waited until I and her had time alone in the dining room and we talked about what was needing to be done" Diary MW*

*"I found time to be alone with her to discuss this in privacy" Diary MW*

Carers also reported that they have never experienced epilepsy. However, being supportive and empathetic with the service user was congruent with their understanding of service users' experiences of communication regarding epilepsy and related issues and this appeared to facilitate their communication:

*"I don't know what is like to live with epilepsy, so I can listen to what [service user] is telling me and help him with anything he needs help with but I don't know what he feels like because I have never been there" Care worker PQ*

This was also highlighted by a service user:

*"He understands how I am feeling; I would like to see somebody going through the same as me" Service user PG*

Service users in particular, have viewed appropriate humour as a recipe for effective communication:

*"I don't have any problems with the nurses and doctors; I often make jokes and laugh with them" Service user PI*

### *Person/individual characteristics*

This relates to the influences of individual personality differences and the role played by gender in communication. It was also apparent that the individual's personality traits and upbringing appeared to influence whether service users and their carers will readily communicate and share information with each other. The service user

and their carer may share a certain personality type or their upbringing and relationships with their parents may influence the way they communicate. This maybe indicative of their willingness to communicate with the carer:

*"....[service user] understands very well. I think we have quite a good working relationship. As service user goes, she is very 'easy-oozy' to get on with" Care worker PO*

*"If I don't trust [carer] is because I have never trusted my parents. I have had a very difficult relationship with my parents" Service user PM*

Moreover, gender was reported by a service user as a facilitating factor of communication. In particular, a female service user has cited her preferences for a fellow female carer as it facilitates her communication with the carer:

*"I found out that I get on well with females than with males" Service user PT*

### *Barriers to communication*

This theme relates to the ranges of barriers that appeared, or have been reported, to hinder service users' and carers' communication with each other and also with health and social care professionals. It was apparent that some factors were reported both as facilitators and barriers at the same time.



**Figure IX. Theme and sub-themes of communication barriers**



There was a wide range of barriers identified as impacting on service users' and carers' communication and also on their communication with health care professionals. Figure IX above shows that the sources of these barriers are multiple; ranging from information exchange such as lack of knowledge, vocabulary and time, lack of alternative communication methods, impairment, the individual person's characteristics and life style choices. Others are stigma, anxiety and the multiplicity of care workers.

### *Perceptions regarding epilepsy*

This theme explores service users' and carers' perceptions regarding the impact of epilepsy on communication and their overall quality of life. In particular, it focuses on the impact of stigma, discrimination and anxiety/fear regarding epilepsy. A very revealing finding was the effect of stigma on communication. In this study, stigma was reported not only as impacting on quality of life but featured strongly as a barrier to communication. Service users and carers have consistently reported their views and experiences regarding epilepsy and the public perceptions of epilepsy. Service users in particular, shared the perception that once you are labelled with epilepsy people will not

communicate with you and thus, you are better off if you are not identified as having epilepsy:

*"You don't have to go round saying I have got epilepsy I have got epilepsy, I like to keep quiet about it, that is why I don't go to some of these meetings because as soon as people know that you suffer from epilepsy, they don't know you not that they don't like you but they don't communicate with you. People who have not got it, it is difficult for them to be with people with epilepsy and you suffer the consequences for something like that but you have not asked for it"*  
Service user PP

*".....my family treat me differently, they push me aside, they don't talk to me, my mother she does not even come near me"* Service user PI

Epilepsy was also described as having a significant impact on a family carer probably as a result of a more emotive relationship with the service user. This reflects public discrimination against people with epilepsy and their carers:

*"She was six years before she can start school because nobody will take her. She has even started the 'fits' at that time but all the time this was her main school, but the headmaster there has never ever, when I was in, call her by her name. I spoke with her and "... oh yes [headmaster] you are the mother of the epileptic" that was quite unacceptable, even then these were some of the things we used to contend with"* Family carer PB

Another interesting finding in this study related to the anxiety/fear that often characterises general medical encounters or consultations. This was also reported by service users and carers as a barrier to communication:

*"She was concerned she might have to go to the clinic without support, but once she understood staff would support her in this activity she was content to go ahead"* Diary MW

### *Information exchange*

Another barrier that was consistently mentioned by both service users and carers' as impacting on communication related to limitations in carers' knowledge and information regarding epilepsy and medication. It was obvious that to be able to communicate successfully, the understanding of what to communicate was perceived as significant. Carers in particular, reported the need for some basic information relating to epilepsy to support their communication with the service user and to enable them to feedback appropriately to health professionals, for example on issues relating to seizure types:

*".....is probably a gap in knowledge because I don't know obviously enough about as much as I should because I work with her and more knowledge for what to look out for, just general knowledge of epilepsy would be ideal" Care worker PAb*

*"I do ask if he is taken his medicine but I don't understand epilepsy as we both have learning disabilities so if he takes a turn I don't know what to do" Family carer PF*

*"I don't understand epilepsy. I understand there are training programmes but I have not been yet" Carer PJ*

*"I asked and I was given a DVD video for a shot and return it but it does not teach me anything. I would like to know more about epilepsy of what to do if he takes a 'turn'. What I need is somebody to come up and sit down with me and tell me more about epilepsy is all I need but everybody is busy and I am not the pushy type of person" Family carer PF*

These views were corroborated by service users:

*"She would like to know more about epilepsy as I would like. And would she get help? That is what she needs to do, to learn something about epileptic fits" Service user PE*

In addition, quality time was reported as a strong factor to every communication encounter in particular, involving service users. However, service users and carers both frequently reported the inadequacy of time as impacting on communication. To some extent, this appears to vary among different health professional groups:

*"I feel is quite quick but am not a pushy person my personality is not to be pushy and forward. I felt [doctor] was like quick out of the door whereas I spoke to [nurse] and he was totally different and he explains everything, what to and what not to worry about"* Care worker PQ

*".....in the majority of the times they listen to you so far and chuck you out of the door with a piece of paper, you get this you get that. You see the doctors nowadays seem to have less time than what they used to"* Family carer PS

*"I will say just maybe sometimes the doctors should listen a bit more but it boils down to how much time they have for each patient. Sometimes you feel especially with someone with learning disabilities if you are talking to appointments sometimes it takes longer than these ten minutes of allocation. And sometimes the person does not communicate that well and you find that it takes a bit longer and you are [carer] a bit feel rushed"* Care worker PO

*"Sometimes the doctors don't just want anybody else; you feel like they have no time for you to speak to, that is why you are holding things in. They don't want to listen, they are that busy, but even if you say I want to sit and have a word they want you out of the door"* Service user PG

Moreover, there were other ranges of barriers reported. In particular, service users have reported their experiences of dealing with multiple care workers as impacting on communication. It appears that frequent changes to shift patterns with different care workers come with different expectations. This does not only lead to communication

mismatch or poor information but is also reported by service users as confusing:

*".....[care worker] does listen to me but then it is when you have more than one person dealing with different medications you get so confused Jerry, you know? You get like one person dealing with your morning ones then you get one person dealing with your lunch time ones and another one dealing with your tea time ones then you get another guy dealing with your bedtime. So is not the proper pattern you know. I get confused because sometimes my brain tells me one thing" Service user PT*

Also, carers in particular have commented on service users' vocabulary deficits. Arguing that technical words or jargon may result in poor communication. Service users may have limited vocabulary and may not understand the medical terms and this may hamper communication. Thus, there is a need to use lay language that can easily be understood:

*"They did not tell me but they have told her so she knew, but is difficult sometimes the medical words are a bit beyond her and if she wants to tell me sometimes she can't always remember the words" Family carer PB*

#### *Lack of augmentative alternative communication*

A less recurrent barrier reported by a carer as impacting on her communication with the service user related to the lack of alternative methods of communication. Carers working with people with learning disabilities need to acquire the requisite communication skills both verbal and non-verbal skill to enable them to communicate successfully. However, a carer in this study has reported her limitations in alternative forms of communication and thus, believes she is unable to communicate in any form other than by verbal means:

*"... [Service user] can 'sign' but I can't so we don't use signs" Carer, PJ*

### *Impairments*

Furthermore, service users and carers may have multiple impairments. These may be physical, cognitive or both. The physically impaired individual may have good understanding but may have difficulties in physically articulating the words:

*"I got told I used to get speech therapist at school and there are some words I cannot pronounce and I get annoyed with myself. I am not annoyed with the person but am annoyed with myself"* Service user PI

*"Sometimes he mumbles and the words are not clear and I try to let him speak slowly"* Carer PJ

*"Sometimes she found it hard to communicate ideas she had but could not verbalise easily"* Diary MW

Also, some service users may be cognitively impaired with limited memory or recall:

*"I have to remind her several time and I was aware I might have been nagging which makes her less likely to complete her job"* Diary MW

*"Sometimes the conversation went onto other matters but I made sure that she is focused by summarizing before we finish our chat"* Diary MW

*"When you are there you don't know what to say but when you go away is so easy to remember what you were going to say"* Service user PP

Nonetheless, carers also reported their own limitations as impacting on their communication with service users. A carer reported that she

also has impairments including learning disabilities and that makes it difficult for her to understand information and to communicate:

*"He shows me the recovery position and tries to let me understand it but we both have learning disabilities. I also have diabetes and he is also trying to understand it"* Family carer PF

People with learning disabilities have been perceived as incapable of communication. This perception was reported by a service user's own carer who was almost overwhelmed that people with learning disabilities as service users could communicate just as anybody else:

*"He is eloquent and he will just hold a normal conversation the same way like anybody else. Very few signs that he is learning disabilities, you can have a normal conversation basically about everything and he will pick up on little things"* Care worker PH

#### *Person/individual characteristics*

Moreover, the very unique nature of individual service user personality, beliefs and/or attitude may act as barriers to communication. For example, service users may choose not to disclose things that he or she considers private and confidential:

*"I don't talk about my epilepsy with anybody; I just keep it to myself because I think unfortunately is not anybody's business"* Service user PI

*"I like to keep some things to myself"* Service user PI

Also, gender was reported to play a significant role in communication. Male gender in this study was perceived by a female carer as a barrier to communication. This female carer perceived her male service user as an individual who is very private, who does not normally disclose everything to women, and who selectively listens to women as and when it pleases him:

*"You have to be a mind reader as he does not tell you everything. But I think I need to know more in case he is in severe pain, but men don't listen to women all the times"* Family carer PF

### *Life style choices*

Finally, although the service users' rights to independence were acknowledged within the data, this was balanced with concerns around health risks: in particular, eating habits which could result from life style choices and may lead to communication break down:

*"She likes diet coke, chocolate and things like that which can be linked to her seizure activity and we kind of discourage her but we cannot really do anything about it if she wants to go and buy it"* Care worker PL

## 5.4 Associative/comparative analysis of the dyads

Table 10. Dyads of service users and carers (dyads in red are family carers).

|                      |    |    |    |    |    |    |    |    |    |    |    |    |    |    |     |
|----------------------|----|----|----|----|----|----|----|----|----|----|----|----|----|----|-----|
| <b>Service users</b> | PA | PC | PE | PG | PI | PK | PM | PN | PP | PR | PT | PV | PX | PY | PAa |
| <b>Carers</b>        | PB | PD | PF | PH | PJ | PL |    | PO | PQ | PS | PU | PW |    | PZ | PAb |

As stated earlier, the epistemological assumptions adopted in this study recognise that individuals' experiences and the meanings ascribed to their behaviour are ultimately linked to the environment in which they live. The design required the researcher to purposefully interview pairs of service users and their carers rather than random sampling of service users and carers who may not know each other. This pairing enabled the researcher to search for patterns of associations or comparative analysis within and between the dyads.

This analysis of the dyads revealed varied characteristics of carers (see Appendix 10). In terms of the caring relationships the majority were care workers. Only four carers were family carers (as highlighted in Table 10). There were also significant variations in the amount and nature of supports from carers (see Appendix 10). Service users who are living in supported housing accommodation have at least two care



workers. These characteristics may all have influenced the experiences of communication reported in this study.

In addition, it was discovered that some family carers also have significant levels of impairment. For example, two carers (PF, PZ) have learning disabilities and one carer (PB) has epilepsy. There were also demographic variations in particular; there were more female participants compared to men (see Appendix 10). This section will look at the relationship of the dyads in terms of: the integrity of the dyads (family carers and care workers); the influences of carers own enduring conditions or impairments on communication; the credibility of the phenomenon experienced or reported by service users and their carers; and the influence of participant's demographic features.

#### *5.4.1 Integrity of the pair (family carers and care workers)*

The researcher adopted the ontological assumptions that realities are multiple and different. Although family carers and care workers may experience the same phenomenon, they may also respond to a phenomenon differently. An isolated phenomenon was stigma regarding epilepsy. Service users have reported stigma of epilepsy as a barrier to communication however, it emerged in this study that stigma was also a phenomenon experienced and reported but only by a family carer as discriminatory and impacting on quality of life:

*"She was six years before she can start school because nobody will take her. She has even started the 'fits' at that time but all the time this was her main school, but the headmaster there has never ever, when I was in, call her by her name. I spoke with her and "... oh yes [headmaster] you are the mother of the epileptic" that was quite unacceptable, even then these were some of the things we used to contend with" Family carer PB*

This may relate to the carer's caring relationship with the service user. Family carers may have a more emotive relationship with the service user; they may have different expectations and therefore, may experience and respond to a phenomenon differently from care

workers. Care workers may have different emotional relationships with the service users compared with family carers.

Moreover, it was also evident that a particular family carer viewed herself with her service user as an inseparable pair and therefore, preferred to be treated as a unit where she could represent the service user when necessary. This may be due to the existence of established family bonds with the service user. Therefore, family carers may want to be more involved in decisions regarding the service user and in particular, may want to serve as an advocate for the service user if permitted:

*".....I tried to change her appointment because she had no time to do it or something and I phoned the reception and say could she change it from this time to that and they said they are sorry they could not do it because it was confidential and that was just stupid because it has nothing to do with medicine. She was just asking to change but I suppose maybe they do get some 'nutters' who would do it for fun but I am her mum. Is stupid because they knew I am her mum they can identify the two of us together. I think if you know the way she is they should be a bit more forthcoming because she can't always relay it to me you know" Family carer PB*

#### *5.4.2 Carers' own impairments*

As mentioned earlier, two of the family carers also have learning disabilities (PF and PZ) and one family carer with epilepsy (PB). Three key elements emerged from the analysis of their interviews and relate to the nature of information provision from health professionals; carers own communication needs; and their dependence on each other to cope with their conditions.

A carer in this study expressed her concerns regarding how epilepsy information is provided. She acknowledged her own learning disabilities as a limitation in her ability to understand information. She has identified the need to have face-to-face interactions with a health

professional who would explain the information packages to enable her to understand. However, this was not provided:

*"I asked and I was given a DVD for a shot and return it but it does not teach me anything about epilepsy" Family carer PS*

*"Somebody to come up and sit down with me and tell me more about epilepsy is all I need but everybody is busy and I am not the pushy type of person" Family carer PS*

Furthermore, this carer also reported how she and the service user self-manage their conditions by teaching each other what to do, for example, during emergency situations:

*"He shows me the recovery position and try to let me understand it but we both have learning disabilities" Family carer PS*

*"I also have diabetes and he is also trying to understand it" Family carer PS*

Moreover, a family carer with learning disabilities also reported her own communication limitations and her experiences with health professionals in the general hospital and the need for familiarity with the health professional to enhance communication:

*"They don't understand me" Family carer PZ*

*"My family doctor (GP) like talking to me, my doctor will say to me how am I doing and I will say am fine" Family carer PZ*

*"She always give a smile she says you are looking healthy today, and I say yes and she says why are you here.....(laugh)" Family carer PZ*

Furthermore, service users also expressed some concerns regarding continuity of care. This relates to the service user's experiences of interacting with multiple care workers which impacted on communication and this may have implications for the provision of

care:

*".....[care worker] does listen to me but then it is when you have more than one person dealing with different medications you get so confused Jerry, you know? You get like one person dealing with your morning ones then you get one person dealing with your lunch time ones and another one dealing with your tea time ones then you get another guy dealing with your bedtime. So is not the proper pattern you know. I get confused because sometimes my brain tells me one thing" Service user PT*

#### *5.4.3 Credibility of the phenomenon*

The associative analysis was extended to determine the credibility of the phenomena reported by service users, family carers or care workers. In particular, regarding how a phenomenon was experienced and reported by the dyads. It emerged from the analysis that for example, dyad (PE) and (PF) are a married couple and have both reported their lack of knowledge regarding epilepsy as impacting on their communication and the management of epilepsy:

*"I would like to know more about epilepsy of what to do if he takes a turn" Family carer PF.*

This was reflected in service user interviews, in which information needs of the carer regarding epilepsy were also reported:

*"She would like to know more about epilepsy as I would like" Service user PE*

*"That is what she needs to do, to learn something about epileptic fits" Service user PE*

In addition, members of dyad (PP, PQ) have both reported the incidence of medication errors as an issue impacting on trust regarding their communication with health care professionals:

*"Medication is funny, there are so many things going on with my medication. For instance, the doctors got mixed up between my medication and my brother's medications, how is that? I try to understand whether I take different, medications" Service user PP*

*"He asked me a few months ago to double check his tablets because he felt the tablets were wrong and I did and the tablets were definitely wrong and we both went down to the doctors to get everything sorted out" Care worker PQ*

Also, the lack of knowledge or limited use of alternative methods of communication was also reported by both members of dyad (PI and PJ):

*"...I have a friend, his name is [name] he translates me to some folk. He comes here to visit me" Service user PI*

*"He [Service user] can 'sign' but I can't so we don't use signs" carer worker PJ*

#### *5.4.4 Demographic features*

In terms of gender, the majority of the participants were females (17) and males (11). In the majority of the interviews, gender was not reported as a significant factor of communication. However, one female service user reported her preferences of female carers as she believes it facilitates communication.

Furthermore, there were significant variations in participants' ages. Although a participant within the younger age range may have different needs and expectations of health professionals, for example, regarding employment and driving, the influence of participants' age on communication was not evaluated. This is because participants' actual ages were not known.

In conclusion, it was evident that the paired data (matching the service user and the carer) has added value by enriching the credibility of the findings. It has provided greater insight regarding how a phenomenon is experienced and reported by both service users and carers and enhances its credibility. A particularly important finding is the endurance of some carers who also have disabling

conditions and the implications this will have on services provision including the provision of carers for people with learning disabilities.

Overall, this study set out to investigate communication regarding health related issues. However, the health related and non-health related findings appear to be interrelated. Specific health related findings related to service users' communication needs and expectations with health care professionals. These include: Knowledge and information regarding epilepsy; Trust and credibility e.g. regarding medication errors and side effects; Involvement in health management; Life style choices e.g. eating habits; and Withholding or concealing of information.

Furthermore, specific non-health related findings include service users' communication with carers. These mostly relate to activities of daily living such as domestic chores, recreational and social events. In addition, there are other communication domains which are either health or non-health related or both. These include elements such as life style choices, perceptions of epilepsy, the individuals' relationship characteristics and interpersonal skills such as gender, empathy and humour. As discussed earlier, effective communication is not only associated with positive health outcomes but may also have some psychosocial benefits. Therefore, poor communication may lead to significant impact on quality of life for both service users and carers.

## Chapter 6: Discussion of the findings

### 6.1 Introduction

This study proposes that effective communication plays a crucial role in the management of people with learning disabilities with epilepsy. However, service users' views regarding communication have been a neglected area. This study is purported to bridge this gap by adopting a paradigm where the participants' views are placed central to the aims and objectives of the study.

The study objectives (as previously stated on page 9) are to:

1. investigate how people with learning disabilities and epilepsy communicate with carers and health and social care professionals regarding epilepsy and related issues;
2. explore the strategies used by carers to communicate with people with learning disabilities regarding epilepsy;
3. determine carers' perceptions of how people with learning disabilities and epilepsy communicate with health and social care professionals;
4. explore communication methods described by people with learning disabilities and their carers;
5. make recommendations on strategies which could be employed by people with learning disabilities, carers and health and social care professionals to facilitate communication, regarding key issues such as seizure management and adherence to medication.

The previous chapter focused on synthesising service users' and carers' views and experiences of communication regarding epilepsy and related issues that addressed these objectives. The findings revealed that people with learning disabilities as service users are indeed capable of communicating and expressing their views on issues that matter to them when given the opportunity. It is evident that service users and carers are well aware of what constitutes effective communication and how to adopt specific strategies to enhance communication. In addition, service users and carers in this

study reported ranges of views and experiences as impacting on their communication with health care professionals.

Six key themes emerged in this study as the main findings which addressed the study objectives namely: communication needs and expectations; 'engagement'; strategies of communication; methods of communication; factors that facilitate communication; and factors that act as barriers to communication. The focus of this chapter is to discuss each of these key findings in the light of the study objectives in a wider context. It does this by linking the findings to existing literature demonstrating the significance of the study and its contribution to knowledge. Within the discussion, participants' quotes will be introduced when necessary to help illuminate or support any argument or claim raised in this chapter. The discussion of each main theme will be concluded with a brief summary highlighting key messages within the theme.

## 6.2 Communication needs and expectations

This theme explores service users' and carers' views and experiences of communication with health care professionals regarding epilepsy and related issues such as seizures and medication, as identified in objectives 1 and 3. It investigates what service users and carers talk about with their health care professionals and their communication needs and expectations regarding health management.

The findings of this study demonstrated the complexities of communication involving people with learning disabilities with epilepsy. The findings suggest that service users have numerous communication needs and expectations with their carers and health care professionals. Although aspects of study objectives seek to investigate service users' and carers' communication regarding health related issues, this appears to be very limited. Service users in this study reported their communication needs with their carers are primarily based on activities of daily living for example regarding domestic chores and social events. The limited communication



regarding health related issues was reportedly linked to a range of factors. One common reason given by service users was that they are self-caring and therefore, engage very little with their carers regarding health management. This reported self-management may be a reflection of services provision in terms of educational interventions including the promotion of independence. This finding may also be an indication that people with learning disabilities, if given the needed support, are able to self-manage. However, it is unclear to what extent service users self-manage their conditions. Furthermore, although it is beyond the remit of this study to investigate how service users self-manage their conditions, a previous study in the general population found discrepancies between service users reported 'self-management' and 'actual self-management' and this may have implications for communication (Buelow and Johnson, 2000). It is argued that service users' self-caring decisions may not necessarily conform to health professionals' advice. Service users may 'self-manage' their conditions to fit into their own lives (Buelow and Johnson, 2000). Community-based adults with learning disabilities who are living independently or supported by carers need to be able to communicate effectively with their carers and health care professionals; and share appropriate information, for example regarding medications.

Carers provide significant support for the service user regarding the management of epilepsy and their information needs are crucially important for communication. In particular, the diagnosis of epilepsy relies upon a first-hand witness account of a seizure to support the diagnosis (Sander, 2003b). Effective communication with the carer may lead to early identification of health related issues such as side effects which in turn, may relieve distress and improve quality of life for both the service user and the carer. However, in this study service users view health management as a role reserved for health professionals.

Also, it emerged from this study that although it may not be perceived as a role for carers to talk about health issues, service users and carers reported unmet communication needs with health care professionals as impacting on their communication. This may be indicative of service users' lack of communication with their carers regarding health management.

### *Epilepsy knowledge and information*

It was evident in this study that both service users and carers considered knowledge regarding epilepsy and medication as a significant tool that may enhance communication but this appears to be limited. This study demonstrated carers' lack of knowledge regarding health management and was supported by service users' reports. Carers need for knowledge and information regarding epilepsy in this study concurs with earlier studies in the general population (McEwan et al., 2007) but has not been reported by people with learning disabilities and epilepsy. Kendall and colleagues also reported similar findings in their study, within an epilepsy organisation, regarding carers' information needs relating to medications and side effects (Kendall et al., 2004). The Scottish Intercollegiate Guidelines Network (SIGN) guidelines for epilepsy recommend that adults and their carers have the right to accurate information about the condition including the specific epilepsy syndrome, its treatment and implications for everyday life (SIGN, 2005).

### *Involvement in health management*

Furthermore, involvement in issues relating to health management with health care professionals was reported as a particular communication need by service users. This study indicated that service users value more egalitarian relationships with health care professionals where they can input on issues regarding their health. It is claimed that most of the NHS policies fit under the banner of patient and public involvement and interactions between individual

patients and health professionals are encouraged (Coulter, 2005). Therefore, improving communication between patients and professionals and a shift away from paternalism to a more patient-focused approach has the potential to improve patient care (Coulter, 2005). In particular, people with learning disabilities in the community may have different communication support needs compared with the general population.

### *Trust and Credibility*

Service users in this study reported the need for information to be honestly and openly discussed with them. However, they perceived the information they receive from health care professionals as insufficient and often contribute little to the discussions. This however, was reported to vary among the individual professionals and also with different professional groups. It is argued that whilst health professionals may be primarily interested in symptom reduction (Keller and Carroll, 1994), service users in this study want to have an open discussion with their health care professionals regarding the management of their conditions where they can input regarding their health.

Patient-centeredness is proposed as a therapeutic alliance (Mead and Bower, 2002). It is claimed that compliance with treatment is not only dependent on the doctor's advice but also on how well it fits into the individual's life (Buck et al., 1997). It is further argued that symptom reduction is not an adequate index for success and therefore, not a sufficient marker of improved quality of life (Perkins, 2001). Therefore, tension exists. Whilst health professionals may be interested in cure and symptom reduction, the primary interests of service users and carers may be on information sharing and receiving the supports and services that they need to improve quality of life (Perkins, 2001; Wilcox and Kerr, 2006). This reflects the philosophy of cognitive behavioural theorists who argue that people make health decisions on the basis of their beliefs. These theorists argue that

choices regarding different courses of action are influenced by two elements: the individuals' subjective views whether a given action will lead to a set of expected outcomes; and evaluation of the outcomes regarding the impacts this may have on individual's daily life (Berry, 2007). This means that people reflect over a particular course of action by weighing the 'pros' and 'cons' before deciding whether or not to engage in particular health behaviour (Berry, 2007; van Dulmen et al., 2007). Community-based people with learning disabilities may want to lead an independent life and to adopt a more consumerist perspective regarding the services they receive. Service users in this study reported the need to have discussions with their health professionals where they can make informed choices regarding their own health. However, this was perceived to be lacking in the current study. It has also been reported that people with epilepsy want information about how to adapt to their condition delivered in a more interactive environment (Elwyn et al., 2003; Poole et al., 2000). Furthermore, it is asserted that what most patients and the public want is the security of knowing that health services will be there when they need them; that their views and preferences will be considered by health professionals; and that they can access reliable information about their condition and the treatment options available to them (Coulter, 2005).

The findings in this study also point to the perceived lack of honesty between service users and health care professionals. This related to the apparent concealing and withholding of information from service users. However, people with learning disabilities are entitled to their rights as consumers of health services and therefore, the right to information regarding treatment plans and opportunities just as anybody else. It is claimed that in the past health professionals commonly withheld health information from patients with patients' tacit consent (Laine and Davidoff, 1996). However, in contemporary health care practice, patients are increasingly expected not only to know their diagnosis but also, detailed information regarding treatment options and prognosis (Laine and Davidoff, 1996). It is

argued that beyond 'honesty is the best policy', the value of information sharing with patients is that it enables patients to participate in health decisions (Laine and Davidoff, 1996). Information for patients is not only a social, moral and human right but has legal underpinnings. For example The Mental Health (Care and Treatment) (Scotland) Act 2003 for 'mental disorder' including people with learning disabilities also places emphasis on service users participation in decisions regarding their health (Scottish Executive, 2003a). It is claimed that patient satisfaction and adherence are ultimately linked to their involvement in the treatment (Martin et al., 2005). It is further argued that patients who feel their healthcare professionals communicate well with them and actively encourage them to be involved in their care are more likely to adhere (O'Malley et al, 2002).

The present study highlighted lack of trust and credibility between service users and health care professionals in particular, relating to medication and side effects. One service user reported lack of trust with the health professionals as negatively impacting on communication. This was triggered off following a medication incident. Service users expressed concerns regarding the medication they receive, fearing that they may be receiving the wrong medication:

*"The doctors got mixed up between my medication and my brother's medications, how is that? I try to understand whether I take different, medications" Service user PP*

The prevalence of medication errors has been reported in the general population (Sulman et al., 2005). It is claimed that medication prescribing deficiencies are the most common cause of actual and potential adverse drug events (Bobb et al., 2004; Lesar, 2002). The majority of service users in this study reported they are self-managing and therefore, the need for effective communication is vitally important to reduce possible medication errors in particular, when communication in this study is reported to be poor.

Furthermore, service users in this study also reported issues relating to lack of trust with health care professionals especially regarding health issues such as side effects. They reported that health care professionals do not appear to believe them when reporting concerns regarding ill health. This finding concurs with a study in the general population which revealed misunderstanding and disagreements regarding attributions of the causes of side effects (Britten et al., 2000). However, to a significant extent, the doctor-patient relationship is dependent on trust; and effective communication is nurtured in trusting relationships. All health professional bodies, for example, the General Medical Council and the Nursing and Midwifery Council both emphasize the need to maintain trust with patients as a top priority. It is claimed that many people with learning disabilities are more likely to be taking multiple medication and therefore, may be particularly susceptible to antiepileptic drug effects such as behavioural, cognitive and cerebral disturbances (Alvarez et al., 1998; Beavis et al., 2007a). However, medication side effects may be difficult to identify or differentiate if the service user is unable to articulate their health concerns and also, if the health professional fails to attribute credibility to the service user reports.

The significance of trust between service users and health care professionals has been widely reported in the literature (Fiscella et al., 2004; Street et al., 2008; Weng et al., 2008). It is claimed that trust is an unwritten agreement between two or more parties for each party to perform a set of agreed activities without fear of change from either party (Shore, 2003). Trust is said to be vital to patient-doctor relationships and with other health care professionals and can mediate important behaviours and health outcomes (Fiscella et al., 2004). However, trust between patients and health providers can manifest in several areas and has been perceived differently by patients. It is claimed that patients who believe they share more similarities with their health care providers in terms of beliefs, values and ways of communicating reported greater trust in their doctors,

more satisfaction with care, and have stronger intentions of adhering to recommendations (Street et al., 2008). Furthermore, the degree to which physicians were patient-centred in their communication do not only reflect patients' perceptions of trust but also predict outcomes (Street et al., 2008). Patients perceive more trust in health care professionals who use more patient-centred communication (Fiscella et al., 2004). Other studies reported trust to be positively associated with the doctors' experiences and also to be dependent on the patient-doctor relationships (Weng et al., 2008). A large population study in the US found patient knowledge and trust in their health care professionals to be the most important variable, strongly associated with adherence; trust was most strongly associated with patient satisfaction with their physician (Safran et al., 1998). Adherence rates were almost three times higher in primary care relationships characterised by trust (Safran et al., 1998). It is claimed that credibility consists of three key elements; competence, trustworthiness and goodwill (Wrench and Booth-Butterfield, 2003). If patients believe their health care professional is competent, honest and truly cares about their welfare, they are more likely to comply with medical directives (Wrench and Booth-Butterfield, 2003). However, there is a need for partnership working and the development of trusting relationships between patients and health care providers.

### *Information sharing*

Moreover, the present study shows that both service users' and carers' communication needs for health care professionals relate to the need for a multidisciplinary approach to health management. People with learning disabilities and epilepsy may have different communication needs that require multidisciplinary collaboration and they need to have information consistently shared with carers and health care professionals. This is because any miscommunication may have detrimental effect on the service user's health. The importance of multidisciplinary approach to addressing the communication needs

of adults with learning disabilities have been captured in the literature (van der Gaag, 1998). A similar study also reported that patients are confused by the conflicting advice from doctors and other sources of information (Britten et al., 2000). It can be argued that people with learning disabilities are particularly vulnerable to medication errors due to possible communication difficulties and cognitive impairments. Therefore, the involvement of carers in medication management may be crucially important. However, carers in this study reported they play limited roles regarding health management with service users partly due to limited knowledge regarding epilepsy and related issues and partly because the service users are self-caring. Furthermore, another tension exists between carers and service users. Whilst some service users would value input from carers, others do not want carers to be involved in health management. Therefore, while promoting independence, effective communication with service users, carers and health professionals must be attained to achieve common goals.

Finally, service users and carers have also reported differing goals and expectations when engaging in communication with health care professionals. It is evident in this study that service users' goals and expectations regarding communication sometimes run counter-productive to those of the health care professionals. Whilst health professionals may be interested in the management of epilepsy, this may not be a priority to the service user; instead, service users may prioritise meeting their socio-economic needs. One service user in this study reported that his communication needs with health professionals largely related to employment with little concern regarding the impact on his epilepsy (for example, the need to get a driving licence that would open the window for job opportunities). This finding is consistent with published studies in the general population that look into epilepsy and employment and the difficulties in placing people with epilepsy in work (Chappell and Smithson, 1998). The protocol for accessing a driving license by people with epilepsy involves a complete seizure remission for a stated period of time.



However, service users may have little understanding regarding the impact epilepsy may have on employment and driving but may perceive this solely as an opportunity that has been denied. This has implications for effective communication to appropriately convey the message for service users to understand the relationship between epilepsy and employment.

In conclusion, the majority of service users in this study reported they are self-caring and do not want to involve the carers partly because of lack of knowledge. It was also evident in this study that service users are well informed regarding communication needs. Service users know what their communication needs are and who is responsible for providing those communication needs. For example, service users in this study do not consider health management as a role for carers but rather health care professionals. Service users' communication needs with health care professionals reported in this study include: involvement in decision-making regarding medication; developing and maintaining trusting relationships with health care professionals regarding health and side effects of medications; and a multidisciplinary approach to health management involving carers to ensure information is comprehensive and consistently shared.

### 6.3 Engaging with carers and health care professionals

This theme investigates how service users communicate with carers and health professionals and also focuses on carers' perceptions regarding how service users communicate with health professionals regarding epilepsy and related issues such as information provision, as stated in objectives 1 and 3. The findings of this study demonstrate that service users have good insight regarding communication with their carers and health care professionals, and the impact of communication on the management of epilepsy. Service users in this study know how to engage with carers and health care professionals, and can evaluate the effectiveness of the communication encounter. The findings show that effective engagement is viewed as a dialogue

between the health provider and the service user which requires the exchange of information between the patient and the health care professional rather than just an information seeking process (Forbat et al., 2009).

Furthermore, effective engagement was largely viewed by service users and carers as a predictor of quality communication. It was evident in this study that effective engagement embodies certain elements which are crucially important to the communication encounter. The effectiveness of the engagement as reported by service users and carers in this study is dependent to a great extent on whether the parties involved in the communication process do listen to each other, whether they understand the information exchanged, the quantity and quality of information provided by health care professionals, and the sufficiency of time allocated for the communication encounter.

Service users and carers reported dissatisfaction regarding their engagements with health professionals and their experiences of communication reported are largely negative.

### *Listening*

Although this was reported to vary among different health care professionals, service users and carers in this study perceived they were not being listened to, and reported this as having significant impact on their quality of life. It is asserted that when patients are being listened to it has a therapeutic effect and is regarded as a healing process (Denham et al., 2008). Other evidence suggests that engaging actively in a communication encounter is beneficial and associated with positive outcomes (Harrington et al., 2004). The significance of listening as an integral part of the communication process has been highlighted previously in the general population (Denham, 2008, Jackson et al, 2003). Other studies reported that in clinical practice patients often contribute very little to the consultation

apart from answering direct questions (Harrington et al., 2004). A study by Zivian and colleagues (2004) reported that people with learning disabilities want to be treated as adults and prefer to engage face-to-face with their GPs. It is claimed that communication is at least, a two way process in which both parties have the responsibility to make the communication encounter a success (van der Gaag, 1998). It could also be argued that people with learning disabilities are more vulnerable to suggestions and are likely to acquiesce (Martin et al., 1997, Perry & Felce, 2004). Therefore, to make the most out of a communication encounter, consideration must be given to good listening skills. This ensures that the message is understood by the parties involved. It is posited that if you listen carefully to the patient, they will tell you the diagnosis (Osler cited in: Denham et al., 2008).

Active listening to patients may involve giving undivided attention to the patients, and listening to both the content and emotion, and responding to feelings. Arguably, 'empathetic listening' is considered as one of the essential ingredients of good clinical practice (Denham et al., 2008). Furthermore, it is claimed that active listening includes a set of non-verbal skills that signifies to the patient that the health professional is listening attentively, these include; leaning forward, being silent, using smiles and nodding to encourage further disclosure (Branch and Malik, 1993). In particular, service users in this study demonstrate a degree of cognitive and communication impairment and may require more time to be able to process information and to elicit the required information. This needs to be taken into consideration as part of providing and creating opportunities for people with learning disabilities to communicate (Sigafoos, 1999).

#### *Quality time with health care professionals*

Quality time with health care professionals was perceived as an essential aspect of engagement; however, this was reported to be lacking by participants of this study. Good consultation time is regarded as an indicator of quality health services delivery (Wilson

and Childs, 2002). Service users and carers in this study reported the need for more consultation time with their health care professionals to discuss any health concerns they may have but often this is not the case and service users are not offered the opportunity by some health professionals in particular some doctors:

*"..... [Doctors] don't want to listen, they are that busy, but even if you say I want to sit and have a word they want you out of the door"*  
*Service user PG*

These findings concur with previous studies in the general population (Prinjha et al., 2005, Cook & Lennox, 2000, Poole et al., 2000). People with learning disabilities have reported the difficulties in engaging when the communication encounter is rushed (Zivian et al., 2004). Due to cognitive and communication impairment, people with learning disabilities may need more time to communicate compared with the general population (Prinjha et al., 2005). Also, research suggests that doctors who consult more slowly are likely to have consultations that include important aspects of care and are more likely to include lifestyle advice and health promoting activities compared with those with limited consultation times (Wilson & Childs, 2009).

#### *Quality information provision*

In addition, service users in this study, have commented on the limited and poor quality of information they receive from health care professionals. Service users value involvement and information sharing with their health professionals. They reported they need detailed information regarding their health including the causes and treatment options in order to reduce anxiety and improve quality of life. However, information provision was perceived to be limited among some health care professional groups.

*"...Doctors are funny people, nurses get down to the 'nitty gritty' and help you, where doctors don't"* Service user PP

This finding is consistent with previous studies in the general population which suggest that patients perceived their information regarding epilepsy as poor, thus impacting on their understanding (Poole et al., 2000). It could be argued that poor health communication is likely to aggravate seizure control and will impact on the psychosocial well-being of the individual and their families. In particular, community-based adults with learning disabilities are entitled to full and accurate information regarding their health care and may want to adopt a more consumerist approach when seeking information from health care professionals.

Moreover, the transition from the medico-biological concepts of disabilities to the bio-psychosocial approach of disabilities has been discussed in chapter 2. Arguably, the paternalistic models of communication where the patient is a passive receiver is now considered to be outdated, paving the way for social models that encourage patient participation in decision making (Stevenson et al., 2000; Taylor, 2009). However, this was not reflected in the findings of this study. The use of medical models of communication in clinical practice appears to be dominant in this study. It is argued that health care professionals may adopt the 'experts' approach and focus on curing the condition for the individual however, service users may be interested in information being discursive and sharing the information with them so that they can input in care management decisions (Keller and Carroll, 1994). Service users and carers in this study want to be actively involved in their health care so that they can express their views instead of being passive recipients of information from health professionals:

*".....I get more information from a nurse than I would from a doctor, they go about it in a different way, they discuss first what is wrong with you as the doctors will tell you what is wrong with you" Service user PE*

These findings are congruent with the philosophy of patient-centred communication which is based on the assumptions that health care professionals must modify their ways of communication by: helping patients feel understood, through inquiry into patients' needs, views and expectations (Epstein et al., 2005). This involves listening to the psychosocial aspects and expanding patient involvement in the management of their health needs (Epstein et al., 2005). Service users reported they want information regarding their health to be fully discussed with them to enable them to understand and make decisions which are consistent with their daily lives.

Nevertheless, the quality of the information provision is dependent on how accessible it is to enable the service user to understand and contribute to the encounter. The information needs to be tailored to the level of understanding of the consumer, particularly for people with learning disabilities who have cognitive and communication impairments and limited recall (Ong et al., 1995). It is argued that information for people with learning disabilities needs to be well presented in order to promote understanding (Rodgers and Namaganda, 2005). Furthermore, it is claimed that people with learning disabilities have low literacy skills compared with the general population and are also known to have limited vocabulary (Ong et al., 1995; Ouellette-Kuntz, 2005). Epilepsy and medication may involve the use of technical and medical terms beyond the understanding of service users and their carers (Ong et al., 1995). Therefore, people with learning disabilities may need information in a clear and simple language free from any jargon to enhance understanding (Martin et al., 2005). Studies reported that non-compliance is very high when patients are unable to read and understand basic written medical instructions (Williams, 1995). Other causes of non-compliance have been reported as related to patients' inability to remember the details of recommendations made to them (Shemesh et al., 2004). However, this could be higher among people with learning disabilities due to cognitive impairment.

In conclusion, service users in this study have strong insight regarding effective communication with carers and health professionals. Both service users and their carers regarded 'engagement' as a strong predictor of effective communication. However, service users' experiences of engagement with health professionals are primarily negative characterised by the influence of the medical models of communication in clinical practice. Specific concerns related to: listening and understanding; quality time and quality information provision.

## 6.4 Strategies of communication

The findings in this study indicated that communication with people with learning disabilities involves a range of strategies. Therefore, to ensure the communication is effective, there is a need to deploy the appropriate communication strategies. An important aspect of the study objectives (2 and 5) was to explore strategies used by carers to communicate with people with learning disabilities and to make recommendations on strategies which could be employed by people with learning disabilities and their carers and health and social care professionals. Both service users and carers in this study have described various communication strategies they use when communicating with each other and also with health care professionals. Service users in this study have reported different styles of communication as strategies to ensure they communicate successfully with their carers.

### *Communication styles*

The literature is populated with studies regarding communication strategies with people with learning disabilities; however, little is known regarding service users' contributions. The need for carers, in particular, care workers, to modify their styles of communication has been well documented in the literature (Bartlett, 1997; Purcell et al., 2000). Studies have commented on the need for carers and health

care professionals to recognise and make changes to meet the communication 'acts' of service users (Bartlett and Bunning, 2000).

This study revealed how service users and carers adapt specific communication styles they perceived effective to promote communication. This finding contradicts previous studies indicating that carers in particular, often fail to adapt their communication strategies with the service user with greater parts of the communication 'acts' falling outside the understanding levels of the service user (Bradshaw, 2001, Purcell, 1999). The study revealed that service users are often interested in the communication outcomes. They are not just dependent on their carers and health care professionals for the success of the communication but they also make determined effort by adopting a range of styles to ensure that the communication is effective.

#### *Behaviour e.g. intimidation*

A significant finding in this study related to certain behavioural strategies employed by service users and their carers to communicate with health care professionals. One service user has reported behaviour such as intimidation as a reflective strategy to effect communication with health care professionals. This finding is a reflection of the notion that when persuasion fails force must be applied. The use of behaviour as a form of communication is not a new finding but in fact has been well recognised. Service users who may be unable to communicate their needs or have their needs denied may resort to specific behaviours in order to express their needs.

'Challenging behaviour' has been given significant highlight as a form of communication difficulty in the literature (Sigafoos, 2000, Kevan, 2003). It is asserted that sudden behaviour changes are always a communication of need or distress (Lennox & Eastgate, 2004). An estimated 10-15% of people with learning disabilities demonstrate



some forms of challenging behaviours (Emerson et al., 2001). However, 'challenging behaviour' is said to be 'socially mediated' aimed to access or escape from social attention (Kevan, 2003, Emerson, 1995, Bailey, 2006). It is claimed that people with learning disabilities see challenging behaviour as an effective communication tool when other conventional forms fail (van der Gaag, 1998). Challenging behaviours are reported more commonly in people with more severe communication difficulties whether receptive or expressive in nature (Emerson, 1995). However, people with mild learning disabilities may demonstrate verbally expressive challenging behaviours. Community-based adults with learning disabilities may want to lead independent lives, and have their views respected; however, failure to express or articulate their needs verbally may lead to frustration and the individual may resort to behavioural strategies to communicate their needs.

Furthermore, the findings in this study suggest that behaviour was not only a tool recognised by service users as a strategy but also by their carers. Assertiveness was perceived by one carer as a behavioural strategy used to effect communication with health care professionals. Although assertiveness has been reported in the literature as a strong predictor of information-seeking desire, little is known regarding carers' use of assertiveness as a behavioural strategy to communicate. It is claimed that assertive adults are more likely to seek detailed information regarding their health (Braman and Gomez, 2004). This implies that carers who want to express their views but feel oppressed or who want to resist the dominance of health professionals may resort to assertiveness in order to be listened to and have their views regarding the service user expressed. However, this has the potential for conflict. The majority of service users in this study reported they are self-caring and may not want to involve carers or have the carer advocating for them in particular, regarding health management.

### *Organisation e.g. planning*

Communication is also perceived as a set of activities that requires some form of organisation and therefore needs to be planned. Carers in this study have also used 'planning' as a strategy that may enhance communication with service users. Planning appears to be congruent with creating opportunities for the individuals to communicate. Adequate preparation prior to any communication encounter is reported to have positive outcomes (Zivian et al., 2004). It is argued that involving people with learning disabilities in communication is dependent to some extent on the abilities of others to create effective opportunities for communication to take place (Sigafoos, 1999). For example, it was evident from the content of the carer communication diaries that communication with the service user may work better when sufficient time is made available for the service user to work at their own pace, so that the encounter is not rushed. This allows service users to contribute to the discussion.

The findings in this study also suggest the environment as a significant component of communication strategies. Generally, it is claimed that certain features of the environment in a health care setting may impact on the application of communication skills and the ability to communicate effectively (Chant et al., 2002). It is claimed that communication involves interaction between the communication partners, and the environment influences the overall communication process (Park and Song, 2005). Therefore, it is essential that a suitable environment that stimulates communication and improves concentration is considered when planning to engage in communication with service users. It is further argued that one way to identifying opportunities for communication is to conduct an assessment or audit of the environment for example, by using an 'ecologic inventory model' for assessing the communication environment to eliminate environmental factors that may act as barriers to communication (Sigafoos, 1999). The quality of the communication environment is also reported to be linked to reducing

challenging behaviour (Hastings, 1997). Numerous environmental factors are known to impact on communication. For example a study by Park and Song, (2005) reported ranges of environmental factors as barriers to communication e.g. noisy environment, being in an unfamiliar situation or location, and the absence of a carer.

In conclusion, it was evident in this study that service users and carers are not only capable of communication but can evaluate the communication process and improvise the communication encounter by adopting specific communication strategies. These strategies include: intimidation as a behavioural strategy to effect communication. Carers in this study also reported that effective communication requires planning to enable the creation of communication opportunities for service users to communicate. This includes choosing a suitable communication environment and allowing sufficient time for service users to communicate at their own pace.

## 6.5 Methods of communication

Communication with people with learning disabilities involves the use of wide ranges of communication means. This study yielded numerous forms of communication which addressed study objective (4). These communication methods ranged from verbal to non-verbal. There was reported dominance of verbal methods of communication over the non-verbal methods in this study.

### *Verbal and non-verbal communication methods*

Despite the wide-spread use of alternative augmentative methods of communication their adoption was limited in this study. Both service users and carers reported preferences for verbal communication as their main method of interacting with each other and also with health care professionals. This may appear to be indicative of the levels of cognitive and communication impairment in this selected population of people with mild learning disabilities. However, this appears to contradict what is reported within the general population. Within the

general population it is asserted that non-verbal communication constitutes about 80% of communication with only 7% being verbal (Donnelly and Neville, 2008). Furthermore, people with learning disabilities are more likely to use non-verbal forms of communication irrespective of the nature and severity of the learning disabilities (Kelly, 2002). This observation reflects a survey by Law and Lester who reported 81% of people with learning disabilities requiring support with their communication (Law and Lester, 1991). However, carers' and health care professionals' communications with service users have been reported to be dominated by verbal communication irrespective of the service user mode of communication (Bradshaw; 2001, McConkey; 1999).

Other authors reported that on average, carers and health care professionals made over twice as many verbal communication 'acts' compared with the service user and are about four times more likely to initiate a communication 'act' (McConkey et al, 1999, Purcell et al, 2000). The reported dominance of verbal communication methods over the non-verbal methods of communication may relate to the fact that most non-verbal forms of communication are involuntary actions, unrecognised and therefore unreported. This can better be determined for example by using observational methods.

Overall, the interest of previous researchers has been on developing health and social care staff communication needs (Jones, 2000; Bradshaw, 2001; Baladine et al, 2007; Pontu & Cole, 2005). However, little is known regarding the service users' preferred communication methods. In addition, the majority of these studies are based on observations of carers and health and social care staff communication in the form of video recording but few face-to-face interviews have been employed for service users to express their views regarding communication (McConkey, 1999; Bradshaw, 2001; Bartlett, 1997).

Despite the popularity of augmentative and alternative forms of communication, in particular, in assisting people with learning

disabilities to communicate, to a very limited extent service users and carers in this study have both reported their awareness of different forms of non-verbal communication such as body language, gestures and photographs. However, no conscious effort has been made to apply them on daily basis. A carer in this study reported her inability to communicate with the service user using sign language. This is a reflection that many people with learning disabilities and their carers are unable to use augmentative and alternative communication methods effectively (Graneheim and Lundman, 2004). The tendency for carers and health care professionals to overestimate service users understanding of verbal language or fail to identify non-verbal behaviours as signs of communication have been reported by previous studies (Purcell, 1999).

### *Pictures and photographs*

The use of pictures and photographs to enhance communication has been widely applied in the general population. It is argued that patients can benefit from pictures in particular, people with learning disabilities stand to benefit the most (Houts,2006; Hourcade et al., 2004). Furthermore, it is claimed that it is not enough to use simple language and offer different modes of communication but they should be supplemented with a variety of supports including cue cards and Talking Mats (Lewis and Porter, 2004).

A significant finding in this study is that one service user has developed a mechanism for coping with his communication deficits by depending on fellow service users to meet his communication needs. This view was supported by the carer who reported her own lack of knowledge regarding alternative methods of communication. This finding is a reflection of carers' training needs regarding augmentative and alternative communication methods. People with learning disabilities who live in institutions may be supported by multidisciplinary professionals including speech and language therapists but these resources may be limited in the community

settings and carers, in particular, may lack the requisite skills or may not be adequately trained to communicate effectively with service users. Carers and health care professionals are encouraged to routinely identify the communication needs of service users to inform the content of local augmentative and alternative communication resources and also to inform staff training needs (Graves, 2007). Bartlett (1997) commented on the need for health and social care staff to recognise and make adaptive changes to meet the communicative 'acts' of service users.

In conclusion, this study yielded a variety of communication methods employed by service users and carers. Although they reported their awareness of non-verbal forms of communication such as gestures and body language, communication between them is primarily by verbal means, but it remains unclear how much non-verbal communication is unreported or unrecognised. Both service users and carers highlighted lack of knowledge regarding alternative communication methods. The findings also show that communication approaches need to be individualised and made more patient-centred because there is no 'fit for all' method of communication. The findings in this study indicated the need for a combination of both verbal and non-verbal methods to enhance communication.

## 6.6 Facilitating factors and barriers to communication

This study yielded numerous factors as facilitators of communication and also some barriers to communication. Aspects of this study's objectives focus on making recommendations for services users, carers and health care professionals (study objective 5). This theme will discuss factors which emerged or were reported by service users and carers as facilitators or barriers to communication, or both.

### *6.6.1 Facilitating factors*

Factors that were reported to act as facilitators of communication appeared to originate from the caring relationships, communication

media, individual interpersonal skills and person characteristics of the individuals.

The need to identify the communication needs of service users to subsequently inform the content of local health organisation communication resources has been highlighted. As mentioned earlier, the focus of previous studies is mostly on staff views regarding communication and how to empower and develop their communication skills with people with learning disabilities; this is to the neglect of service users' views regarding communication (Purcell, 1999; Banat, 2002; McConkey, 1999). In this study, service users demonstrated good insight and expressed their views regarding factors that facilitated their communication with carers and also with health care professionals. This has not been previously reported in the literature in particular, by service users.

#### *Communication media*

One service user in this study reported the value of using pictures and photographs to supplement communication. This finding regarding the role of pictures to enhance communication is consistent with previous research findings. For example, Talking Mats has been widely applied in the field of learning disabilities to elicit responses and the views of service users (Murphy, 1998, 2006). Similarly, within the general population, photographs and pictures have been consistently used to enhance health communication. Published work demonstrates that adding pictures to written and spoken language can increase attention, comprehension, recall and improve concordance (Houts et al., 2006). Pictures and photographs may also be used as an alternative, or along with spoken word, to enable responses to be elicited more spontaneously and also, to keep the communication focused on key issues or items.

### *Person characteristics*

Other factors reported as facilitators for communication in this study related to the characteristics of the service user and the carer. Gender was reported by one service user as an influential factor of communication. The role of demographic characteristics in communication has been reported in the general population but little is known regarding people with learning disabilities. Gender differences have been reported with women showing greater preference for detailed information about their health compared with men (Sanchez et al., 2009). Therefore, service users' gender preferences should be taken into consideration in any communication encounter. These findings also reflect previous studies regarding the role of gender in a medical encounter. Patients visiting female and male physicians have reported different experiences. Female physicians are reported to use more partnership language, be more empathetic and ask more questions about medical and psychosocial issues (Hall et al., 1994; Meeuwesen et al., 1991). Overall, female primary care physicians engage in communication that is patient-centred and spend longer time than their male colleagues (Roter et al., 2002). These differences may result from the differences in men's and women's communication styles and perceptions (Street, 2002).

### *Relationship characteristics*

This study also suggests that the duration of the caring relationship facilitates communication. The length of time or the duration of care enables the development of familiarity and this facilitates the building of rapport and thus enhances communication (Mauksch et al., 2008). This period of familiarity may also allow the individuals to understand their own communication styles and this will inform the relevant communication strategies to enhance the communication encounter.

Similarly, it was also evident in this study that existing 'family bonds' between some service users and their carers were reported as a facilitating factor for communication. However, it is claimed that the



caregiver-service user relationship reflects a 'surrogate family bond' mimicking a 'biological family bond' but lacks the emotional bonds that normally characterise family carers (Sumaya-Smith, 1995). Family carers may share similar cultural heritage with the service user and may have developed from infancy unique ways of communicating with each other. However, only a few of the carers in this study are family carers, the majority of service users living in supported accommodation were supported by care workers.

In this study, service users viewed specialist learning disabilities professionals and GPs who have interest in learning disabilities as good communicators when compared with professionals in the general hospitals. A study by Mills et al, (1999) reported that a primary care-based specialist nurse-led service suggested improvement in communication compared with non-specialist nurse encounters. The role of GPs with a special interest has been recognised and can be extended to include value of specialist consultants and epilepsy specialist nurses (Nocon and Leese, 2004). However, specialist services may be lacking especially in community settings. It appears in this study that GPs with interests in learning disabilities may have acquired special communication skills to enable them to communicate with service users. Other studies suggested that GPs will be able to provide better quality care if they receive further education and training regarding people with learning disabilities (Webb and Stanton, 2009). However, many health care professionals often lack the specialist skills and resources required to work with people with learning disabilities (Webb and Stanton, 2009).

Furthermore, familiarity and the establishment of working relationships between the service user and their GP appear to facilitate communication. People with learning disabilities have been encouraged to use the same GP to enhance familiarization with the individual communication style (Zivian et al., 2004). These findings concur with a study in the general population which indicated that patients prefer health professionals who communicate a caring

relationship, for example, by making patients feel valued as individuals who can interact and share information freely with their health care professionals (Wright et al., 2004).

### *Interpersonal skills*

This study also shows empathy to be a facilitator of effective communication. The relationship between empathy and communication has been reported in the general population. It has been noted that patients seldom verbalize emotions directly; instead, they offer clues until they are invited to express those emotional components (Suchman et al., 1997). A basic empathetic skill is that carers and health care professionals are able to recognise these unexpressed feelings, encourage their exploration, (Finset and Mjaaland, 2009; Suchman et al., 1997) and be supportive by using empathy to show that they understand the patient's experiences and how the patient is feeling (Maguire and Pitceathly, 2002). A similar study revealed that service users prefer professionals who can demonstrate warmth and show interest in them (Zivian et al., 2004). Service users may be more willing to invite carers and health care professionals into their world when there is the display of emotional connectivity between them. The sharing of emotional feelings may also lead to good therapeutic relationships. An empathetic encounter as argued, is one that enables familiarity and understanding (Suchman et al., 1997).

Empowerment was highlighted as a factor that enhances service users' involvement in communication in this study. The majority of service users reported they are self-managing and that the need for continuous empowerment to enable them to communicate is essential. This is a reflection that when people are encouraged to take ownership of their health they may be more inclined to talk about issues that impact on their health. Empowerment also reflects the provision of choices as it enables people to take responsibility for their own decisions. The need to take responsibility is part of one's

personal development, but people with learning disabilities are at risk of being denied this right of responsibility because of society's perception that people with learning disabilities may be unable to communicate. Carers and health professionals have been urged to facilitate the patient's right to choose, even if there are communication difficulties (Lennox & Eastgate, 2004). Empowerment reflects guidelines that adults with epilepsy and their carers should be empowered to manage their condition as much as possible (NICE, 2004). It is claimed that by empowering people with learning disabilities to learn to take responsibility it will enable carers and health care professionals to identify more effective ways of supporting the service users.

Furthermore, humour was reported as a factor that sets the pace for any successful communication encounter. A health care professional who displayed a sense of humour was seen as a catalyst for effective communication by a service user. Humour relates to the ability to see the funny side of a situation. Humour is claimed to have positive effects both on the person's physiology and psyche (Astedt-Kurki and Isola, 2001). In particular, empathetic humour generates a stronger therapeutic environment and foster a stronger physician-patient relationship (Berger et al., 2004). It is commonly acknowledged that judicious use of humour can facilitate communication, promote bonding and enhance patient satisfaction (Berger et al, 2004). Overall, these findings are consistent with a study by Wright and colleagues (2004) who reported that communication is enhanced when health professionals communicate by empowering the patient and displaying natural idiosyncrasies for example through the sensitive use of humour. Also, perceived physician humour has strongly been linked with physician credibility, compliance-gaining strategies and patient satisfaction (Wrench and Booth-Butterfield, 2003).

Carers in this study also highlighted the need to use accessible language and create opportunities for enhanced communication.

Accessible information for people with learning disabilities has been highlighted in previous studies (Owens, 2006; Rodgers and Namaganda, 2005). Accessible language may play a part in providing choices and removing communication barriers (Owens, 2006). Although the definition of accessibility may vary, it is important that the information is tailored to meet the communication needs of people with learning disabilities. This may involve trying various means and methods of communication. Communication may be more accessible when it is delivered on an individual basis. Individualised communications are more patient-centred and provide the opportunity for a one-on-one interaction with the service user. Service users in this study have reported different communication needs which may involve identifying and prioritising each individual's communication strengths in order to eliminate barriers and to optimize communication.

In addition, it was evident in this study that people with learning disabilities are more likely to have some degree of cognitive impairment and may benefit significantly when the message is reinforced. The provision of reinforcement for the appropriate communication response is consistent with the findings from previous studies (Kaiser et al, in: Sigafoos, 1999). Reinforcing the message may enhance the communication by ensuring that the message is understood by the service user. However, it is claimed that health professionals who use only reinforcing communication are less persuasive and induce less compliance than professionals who use both reinforcing (positive) and non-reinforcing (aversive) communication strategies. The study argues that patients are more likely to comply with health professionals who provide arguments for prescribed treatments when compared to those who merely try to apply reinforcing behaviours (Klingler and Burgoon, 1995).

In conclusion, service users and carers are aware of a range of factors that facilitate communication. Although some factors in this study relate to service provision, the vast majority relate to accessible

information including pictures and photographs. The individual personality traits, demographic features, familiarity and duration of the caring relationships were also reported as facilitating factors of communication.

### *6.6.2 Communication barriers*

The findings of this study suggest that people with learning disabilities are more vulnerable to communication barriers when compared with the general population due to cognitive and communication impairments. This study yielded a range of factors as communication barriers between service users and their carers and also with health care professionals. A significant number of these barriers originated from the individual and society's perceptions of epilepsy, exchange of information, limited use of augmentative and alternative communication methods, service user and carer impairment, certain individual person characteristics and also the service user's life style choices.

Studies that investigate communication barriers to involve the views of people with learning disabilities are lacking within the UK population. Review of the literature indicated a dearth of research that investigated service users and carers' views regarding barriers to communication.

#### *Perception of learning disabilities and epilepsy*

An important communication barrier identified in this study related to how learning disabilities and epilepsy is perceived by the general public and the effect it has on the bearers of these conditions.

People with learning disabilities in this study reported their experiences of stigma not relating to their disabilities but rather with the co-existing epilepsy. It is claimed that stigma bearers are often unable to successfully challenge this negative difference ascribed to them partly because they themselves accept the premises and the

values which underlie their discredited social identity (Goffman, 1963). This may imply that people with learning disabilities in this study have come to terms and have identified themselves with their disabilities. They no longer see learning disabilities as a label but rather are stigmatised by the co-existing epilepsy.

Although stigma has been reported in the literature but often as an index of quality of life which may not relate to communication difficulties (Jacoby, 2002). However, in this study, service users have reported stigma as a strong barrier to communication. Service users reported their preference to hide their epilepsy as a mechanism to facilitate communication. They reported that when people get to know that they have epilepsy they will not communicate with them. Therefore, to ensure the continuity of communication, service users perceived it was best if people were not aware they have epilepsy:

*"You don't have to go round saying I have got epilepsy I have got epilepsy, I like to keep quiet about it, that is why I don't go to some of these meetings because as soon as people know that you suffer from epilepsy, they don't know you not that they don't like you but they don't communicate with you"* Service user PP

Findings in this study reflect available literature that people with epilepsy frequently use concealment as a strategy for mitigating the negative impact of their condition in social encounters (Ablon, 2002; Goffman, 1963; Susman, 1994). In a recent study, Killınc and Campbell (2009) reported that people with epilepsy perceive stigma by feeling different from the rest of society, implying that they hide their condition as a way of managing the stigma and thus, the need to renegotiate their social identity.

This study also demonstrated that carers perceived their experiences with epilepsy as discriminatory:

*"She was six years before she can start school because nobody will take her. She has even started the 'fits' at that time but all the time this was her main school, but the headmaster there has never ever,*

*when I was in, call her by her name. I spoke with her and "... oh yes [headmaster] you are the mother of the epileptic" that was quite unacceptable, even then these were some of the things we used to contend with" Family carer PB*

This reflects some of the views held by society regarding epilepsy. In the past people with epilepsy were discriminated against because epilepsy was perceived to be associated with evil spirit. A recent study among an ethnic minority group in England revealed that people still stereotyped epilepsy as caused by the devil (Ismail et al., 2005). Negative perceptions regarding epilepsy and seizures prior to diagnosis have also been identified as a contributory factor to stigma leading to reduced social interactions (Paschal et al., 2005, 2007).

Overall, these findings have implications for education. It is claimed that stigma may be created and nurtured by negative attitudes and statements by the family, children in school and the neighbourhood, doctors and other medical professionals as well as the general public including the media (Ablon, 2002). It is asserted that family attitude can be particularly destructive as reported in this study:

*".....my family treat me differently, they push me aside, they don't talk to me, my mother she does not even come near me" Service user PI*

These behaviours and attitudes of family members towards people with epilepsy are reported in the literature (Ablon, 2002). Research into people with epilepsy and their families indicated that those who cope well with the condition in most cases exhibit a commonality of biographical features and ideologies. The most important feature being unconditional family support and clear intra-family communication (Ablon, 2002); positive parental communication promotes confidence in the individual (Ablon, 2002).

Furthermore, it is claimed that one common factor that may explain these negative attitudes and behaviours from families is the lack of

knowledge regarding epilepsy (Ablon, 2002). The public needs to be sensitised regarding epilepsy in particular, the need to protect and encourage people with epilepsy to live a 'normal' life (Killinç and Campbell, 2009). It is argued that to ensure that people with learning disabilities are adequately supported there is the need to embrace both the principles of social inclusion and social capital. Social capital principles encourage the empowerment of people with learning disabilities through promotion of positive relationships whilst challenging society and media stereotypes through education (Bates and Davis, 2004).

The findings of this study also suggest carers' perceptions regarding the abilities of people with learning disabilities as a barrier to communication. One carer in this study forwarded the assumption that people with learning disabilities are less capable of communication:

*"...very few signs that he is learning disabilities, you can have a normal conversation basically about everything and he will pick up on little things" Care worker PH*

It could be assumed that carers with these stereotyped ideas may engage with the service user with the belief that they are incapable of communication. This assumption reflects the suggestion that disability arises from the social and physical barriers imposed by society rather than the inability of the individual to communicate (Van der Gaag, 1998). This is despite the current era when numerous research findings demonstrate that people with learning disabilities are capable of communication and expression of their views (Murphy, 2006) and can determine a research question (Young & Chesson, 2006). Yet people with learning disabilities are still perceived as incapable of expressing their views. It is argued that the way people with learning disabilities are perceived by others may influence their capacity to contribute to the development of social capital and their own social inclusion (Bates and Davies, 2004).



### *Epilepsy and anxiety*

Furthermore, anxiety normally associated with the consultation encounter appears to impact on communication between a service user and some health professionals in this study. Graugaard and colleagues (2003) study in the general population reported on the importance of factoring patient personality and emotional characteristics into consideration when evaluating patient's communications with health professionals. It is argued that patient satisfaction with medical communication in a medical setting is not a simple measure of communication skills and how well the communication is structured; the anxiety associated with it and the patient's ability to cope with the stress and anxiety should also be taken into account (Steptoe et al., 1991). Anxiety regarding medical consultation is common in the general population. Medical encounters are associated with many uncertainties, in particular, regarding the aetiology and prognosis of the condition. How the condition may impact on everyday lifestyle choices may lead to increased anxiety which may influence the communication encounter between patients and practitioners.

### *Information exchange*

Another significant barrier that emerged in this study relates to carers lack of knowledge regarding epilepsy and related issues. This finding is consistent with previous study findings (Kendall, 2004). As mentioned earlier, service users are entitled to accurate information regarding epilepsy to enable them to exercise choices as consumers of health services, in particular, regarding treatment options. However, service users would only be able to make these consumerist decisions if they have the knowledge and detailed information regarding their health. Furthermore, carers spend significant amount of time with the service user. Therefore, it is imperative that they possess basic knowledge and understanding of epilepsy and medications to adequately support the service user and also to facilitate communication. They could then feedback information

appropriately to health care professionals for example, in the event of seizures or missed medications. It is crucially important that the carer is able to adopt safety measures including the administration of first aid treatments during emergency situations.

A central barrier to communication reported by both service users and carers in this study related to the limited time spent with health care professionals. People with learning disabilities may take longer time to process information and to communicate compared with the general population. Therefore, the amount of time allocated for communication encounters with service users with learning disabilities can be both a facilitator and a barrier to communication. This finding appears to be consistent with earlier studies which reported that people with learning disabilities and epilepsy require more consultation time with their health care professionals to discuss their treatments (Prinjha et al., 2005). Cook and Lennox also identified limitation in consultation time as a barrier to good quality care for people with learning disabilities (Cook and Lennox, 2000).

Another study by Zivian et al., (2004) indicated that people with learning disabilities reported the value of having sufficient consultation time and the encounter not rushed, so that they can be listened to by health care professionals. However, this is likely to have implications on the individual health professional's caseload and will impact on performance targets. A study by Balandin et al., (2007) revealed that service users' communication experiences were more positive when nurses had time to interact with them. This will enable a more effective engagement with the service user and allow in-depth exploration of the patient feelings.

Moreover, the findings in this study suggest multiple care workers can be a barrier to communication. Service users who live in supported accommodation have described their experiences of interacting with multiple care workers as impacting on their understanding. Individual care workers may have different communication styles and may need

to adjust their styles of communication. However, service users in this study have played a significant role by varying their communication skills to match those of the care workers. Multiple care workers may also impact on information provision. Therefore, there is a need to ensure consistency in the provision of information among care workers. Poor communication between care workers may lead to serious health consequences for service users, in particular regarding health management.

In addition, carers expressed concerns regarding the service users' lack of vocabulary as a barrier to communication. The prevalence of medical language over the use of every day language has been reported in the literature (Ong et al., 1995). The use of jargon and technical language by health professionals may lead to poor communication with service users. Service users in this study reported limited vocabulary and difficulty in understanding medical terms used by health professionals with consequent impact on their communication with health professionals and carers. Therefore, health care professionals have been encouraged to counsel in simple language understandable by people with learning disabilities (Zivian et al., 2004).

#### *Limited augmentative and alternative communication*

This finding reflects the need for alternative and augmentative communication methods to minimize any possible communication barriers between carers and service users. Technological advances have led to numerous forms of communication aids. User-friendly communication devices have been developed to include voice output devices for people with learning disabilities (Beukelman, 1998; Hourcade et al., 2004). The role of pictures and photographs to facilitate communication has been extensively discussed in the literature. People with learning disabilities may have cognitive and communication impairments and the use of pictures may facilitate recall and elicit information spontaneously. Study findings indicate

that, given adequate opportunities and effective methods, people with various learning disabilities and communication impairments are able to offer informative and reliable accounts of their opinions (Kroese et al., 1998). Visual representations such as pictures and photographs facilitate communication and reduce acquiescence and 'recency effect' (the increased effect of recalling most recent words) (Kroese et al., 1998).

### *Impairments*

Furthermore, service users and carers also associated some communication barriers to the underlying impairments of both the service user and the carer. These impairments may be both physical and cognitive. Service users described the difficulties involved in physically articulating the words. Cognitive and memory loss may also contribute to poor communication. One carer also relates her communication difficulties to her own impairments (learning disabilities) which she perceived acted as a barrier to her communication with the service user.

### *Person characteristics*

Moreover, the findings in this study also suggest that the individuals' personality differences may influence the way they communicate with others. This finding reflects previous work in the general population but has not been reported by people with learning disabilities. Sanchez and colleagues study in the general population regarding personality differences reported that patient preferences for communication correlated with personality variables (Sanchez et al., 2009). It is argued that personality characteristics may affect how patients view information given to them about their condition and their ability to cope with it and this may influence their communication preference and the need for support (Sanchez et al., 2009). People with high extroversion preferred to receive more detailed health information and demonstrate the need for support from health professionals (Sanchez et al., 2009) compared to

individuals who have introvert personalities. Similar studies suggest personality variables as important in predicting patient preferences regarding their relationship with their doctors (Braman & Gomez, 2004).

In addition, the study demonstrated that certain demographic features may act as barriers to communication. For example, gender differences between the carers and the service users were reported to act both as facilitators and barriers to communication. One service user in this study reported she communicates more effectively with females compared to males thus rationalising her preference for female carers. These findings concur with existing studies in the general population that report the links between patient demographic characteristics and communication (Benbassat et al., 1998). Previous studies in the general population indicated that male and female patients differ in the way they elaborate complaints (Meeuwesen et al., 1991). A similar study finding suggests that women show a greater need than men for information regarding diagnosis and treatment (Butow, 2009).

### *Life style choices*

As mentioned earlier, there are striking health disparities between people with learning disabilities compared with the general population (Walsh et al., 2003). It is claimed that increased longevity means adults with learning disabilities in the community are more likely to encounter health risks compared with those in residential settings (Walsh et al., 2003). People with learning disabilities are entitled to their rights including the choice of food and other health promotional activities. Carers in this study acknowledged service user rights to independent life styles; however, this was balanced with concerns around health risks in particular, regarding choices of food.

Service users expressed concerns regarding the difficulties in communicating health risks against the individual's right of choice to

food. This finding reflects a range of health risks among people with learning disabilities. It is claimed that the proportion of people with learning disabilities who are overweight and obese is higher than the general population (Rimmer and Yamaki, 2006). A health screening exercise in a UK cohort of 464 individuals with learning disabilities aged 10 years and above found 64% as either overweight or obese (Marshall et al., 2003). Although no differences were reported in terms of setting, other studies claimed that adults with learning disabilities living with family carers have a higher incidence of being overweight than those in residential settings (Rubin et al., 1998). Similarly, a study in a US population suggests that adults with learning disabilities who live in a less supervised setting (e.g. family households) have significantly higher obesity compared to individuals who reside in more supervised settings (e.g. institutions) (Rimmer and Yamaki, 2006). These differences may reflect access to health promotional activities, supervision and support. Furthermore, it is argued that although weight gain or loss is not an integral part of epilepsy, sedentary lifestyles can contribute to weight gain (Marshall et al., 2003). However, some antiepileptic medications are reported to be associated with weight gain (Ben-Menachem, 2007). These circumstances may put people with learning disabilities and epilepsy at higher risk of obesity leading to increased risk of seizures (Huang et al., 2008). Therefore, it is recommended that health personnel such as general practitioners, nurses and health promotion staff need to work in partnership with carers and service users to create more accessible and active lifestyle options (Marshall et al., 2003).

In conclusion, the perceptions of communication barriers between service users, carers and health care professionals in this study are multifactorial and related to: health services, the impairment (learning disabilities), public perceptions regarding epilepsy. Specific examples include: lack of knowledge of epilepsy and medications; limited consultation time; stigma regarding epilepsy; limited vocabulary. Others include personality traits and certain demographic characteristics such as gender.

## 6.7 Implications of the study findings

### *6.7.1 Introduction*

It is argued that the impact of any research finding is dependent on its ability to transform beliefs, values and/or policy assumptions within the relevant audiences (Lomas, 1990). This section will discuss the overall implications of the study findings in particular, for health policies, clinical practice, and education.

### *6.7.2 Implications for policies*

In the past decade, tackling health inequalities has been high on government agenda across the UK, characterised by health policies. Strong emphasis has been placed on patient views as consumers of health services, with the focus on partnership between service providers and consumers (Scottish Executive, 2003b). The discourse of consumerism where patients' views are placed centrally in the delivery of health services has long been regarded as an important aspect of health consultations (Lupton, 1997). This view reflects health policies forwarded by the Scottish Government and in England by the Department of Health. Patients are seen as key drivers of change and are the fundamental source of the definition of quality (Scottish Executive, 2003b). This reflects other policy documents specifically focused on people with learning disabilities which highlight the need for people with learning disabilities to be involved in the provision and delivery of their health care needs: for example, *'The Same as You? A review of services for people with learning disabilities'* (Scottish Executive, 2000), *Valuing People Now. A new three-year strategy for people with learning disabilities* (Department of Health, 2009).

In particular, *'The Same as You?'* (2000) was published with a ten year plan of action focused on valuing people with learning disabilities as individuals and involving their views in informing the provision of

the services they require. Although this is yet to be reviewed, the findings of this study suggest significant failings of this policy agenda. Service users in this study reported lack of involvement in their own health management and therefore, they are not enjoying full benefit of these policies. This may relate to a range of factors impacting on health policy delivery. It is imperative that policies are formulated based on robust research evidence; however, the implementation of policies in clinical practice sometimes poses a significant challenge. It is argued that policies are not always implemented because they represent the 'best' ideas but because of their suitability within a particular policy frame (West and Scott, 2000). It is further claimed that once a policy is on the agenda, an 'implementation gap' may occur for example, between the national and the local organisations (Exworthy et al., 2002). The policy may face resistance at both local and national levels and may have to compete with local philosophies.

A number of models have been used to explore policy outcomes in clinical practice. In particular, the Kindon model of 'policy streams' has been widely applied (Kindon, 1995 in: Exworthy et al., 2002). The Kindon model is commonly used to investigate how opportunities for policy implementation are created and could also be destroyed. This model is based on the assumption that policy 'windows' open and close through coupling and decoupling of three 'streams'. These are: problem, politics and policies streams. In the 'problem stream' issues only become problems when recognised as such by government or policy makers, for example through research findings and publications, key events and feedback from current policies. The 'political stream' is made up of both national and local factors such as interest groups lobbying and competing powerbases, organisational interests, general elections, political manifestos and agendas. These factors are said to be influenced by bargaining and consensus building. Finally, the 'policies stream' comprises a range of proposals and solutions forwarded by interest groups and policy makers. This is based on the assumption that policies float in the 'primeval soup', waiting to be chosen. It is argued that all these three domains must



remain separated until coupled by chance, for example through political election or organisational cycle e.g. staff turn over or by the actions of a policy entrepreneur (Exworthy et al., 2002). It is claimed that when the national agenda fails to couple with the local agenda, the high expectations for a particular policy, say at Scottish Parliament, may be dashed at the local level (Exworthy et al., 2002). Furthermore, it is argued that policies are time bound and the timing needs to be right and also resilient to unforeseen circumstances that may impact on the policy delivery (Rafferty and Traynor, 2004). In particular, if the current economic crises continue, prime funding from central government may be reduced leading to enormous pressure on health boards. This overall, will have implications for frontline staff in clinical practice.

### *6.7.3 Implications for clinical practice*

This study has demonstrated the crucial role of effective communication and the need for involving service users and their carers in communication regarding the management and delivery of health services. The findings suggest that effective communication with people with learning disabilities is akin to a reflective model of events that requires self-assessment and awareness of individual communication needs and skills when engaging in communication with people with learning disabilities and epilepsy.

**Figure X. Reflective model of communication**



The above model suggests that communication with people with learning disabilities requires initial assessment and reflection of all the six stages of the model prior to any communication encounter.

First, service users have reported different communication needs and expectations with health care professionals. It is evident in this study that service users' communication needs and expectations of health care professionals may not only be related to health management but may largely be linked to the individuals' psychosocial aspects of daily living. Service users in this study reported the need to develop a trusting relationship with their health professionals. They value health professionals who are honest and will provide them with credible information regarding their health care.

Second, it was evident in this study that service users are more than capable of evaluating the effectiveness of their communication with carers and health care professionals. However, people with learning disabilities as a sub-group of the general population may require extra support to enable them to communicate. For example, service users and carers in this study reported the lack of time for health care professionals to communicate with them and also to enable them to contribute to the communication encounter. They reported the need

to be involved in communication regarding the management of their own health and for information to be consistently shared with them. Therefore, health and social care professionals may need to reflect on how to engage effectively with service users prior to any communication encounter by providing sufficient time for service users to contribute to the discussions.

Service users and carers have both described ranges of communication strategies they adopt to communicate with health care professionals. Therefore, there is a need for carers and health professionals to work collaboratively with service users to identify strategies and factors that may be useful in terms of facilitating communication. In particular, although the most preferred method of communication in this study was reported to be verbal, some service users suggested the use of augmentative and alternative methods of communication, such as pictures and photographs, for consideration in clinical practice in order to enhance communication. Moreover; numerous factors have been reported as barriers to communication which need to be reflected upon. Communication with people with learning disabilities is complex and challenging. The findings of this study demonstrate that every individual is different and communicates through different means. Therefore, there is a need for practitioners constantly to anticipate possible communication barriers and adopt appropriate measures to reduce these barriers to enhance communication.

#### *6.7.4 Implications for education and training*

The finding in this study reflects the difficulties in communication with people with learning disabilities as a sub-group of the general population, but this remains unrecognised by higher education in the education of health professionals. Following de-institutionalisation, there are ever growing numbers of people with learning disabilities in every facet of our communities who are receiving primary care services. It is inevitable that all health care professionals will come

into contact with people with learning disabilities. Therefore, the awareness of the communication needs and expectations of people with learning disabilities is vitally important for all health care professionals.

Also, there is ongoing training of health care assistants across parts of the UK in an effort to supplement and augment some of the responsibilities placed on health care professionals, in particular, doctors and nurses. However, the findings demonstrated that service users have different communication needs of different health care professionals. They know what they want and who to approach for their needs. Service users and carers have also reported different experiences and expectations for different health care professionals and this may apply to health care assistants. This is because the degrees of care provision by health care professionals are different in context and content.

Furthermore, the findings in this study highlight carers' training needs regarding epilepsy knowledge and information to enhance communication, although there remain unresolved tensions. Some service users and carers have expressed the need for knowledge and information regarding epilepsy. However, other service users reported they are self-caring and do not want carers to be involved in health management. Besides, some service users do not regard health management as a role for carers. This is despite the reported crucial roles carers' play in supporting people with learning disabilities. In particular, the presence of epilepsy may require additional support from carers in the management of seizures and medication. Furthermore, some carers in this study reported their own disabilities as impacting on communication and their abilities to understand information. This will have strong implications for health professionals when providing information for carers to support caring roles. Notwithstanding this, the debate regarding the role of carers in health management prevails. However, it is important to recognise that

individual service users are the best authorities of their lives and are entitled to all decisions regarding their own health.

It could also be argued that the majority of concerns expressed in this study by service users regarding communication and health services provision may be directly or indirectly linked to the availability of adequate resources. This is because limited resources can impact negatively on service provision and delivery. In addition, people are living longer and life expectancy is increasing; this will put further constraints on the availability of resources to meet the demands of consumers. It is therefore essential that as individual professionals and as health organisations, there is a need to embark on a search for alternatives regarding how services may best be delivered, for example by adopting other philosophies and theories.

Although the findings in this study may relate to policies and resources, others of significance reflect the individual professionals and organisational work ethos and culture. As individuals we may not only be resistant to change, but may also be amenable to change. The findings suggest that limited resources could be put to good use to improve patient care if we reassess our work culture as individual health professionals and as health organisations.

There is a growing body of knowledge which suggests that social approaches to health organisations in the delivery of public health may have significant potential for improved quality of life (Morgan and Swann, 2004). In recent literature, the concept of social capital has gained popularity as a measure of health inequalities (Kawachi et al., 2008). It is claimed that social capital can act as a strong buffer against socio-economic disadvantage by reducing the effect of the lack of economic resources (Campbell, 1999 in: Exworthy et al., 2002). It is further claimed that for people with learning disabilities to lead fulfilling lives in communities, the principles of social inclusion and social capital play complementary roles (Bates and Davis, 2004).

### *6.7.5 Social capital*

Social capital with its origins in sociology has been used in different contexts but is generally referred to as the establishment of social networks, family connections and bonds, trust and reciprocal relationships, positive attitudes to community institutions that include, participation and civic engagements (Coleman, 1988; Morgan and Swann, 2004; Putnam, 1993). Coleman argues that social capital is not a single unit but consists of a range of different entities with two elements in common (Coleman, 1988). Both include some aspects of social structures which facilitate certain actions of actors whether individuals or corporate actors within the structure (Coleman, 1988). Social capital includes bonds between individuals: both primary groups, such as networks of families, friends, neighbours and the community as a whole; and secondary groups, which include voluntary organisations and civic associations that make it possible for individuals to achieve a variety of goals (Kunitz, 2004). It is argued that at the primary level, social integration and emotional support influence morbidity and mortality; and at the secondary level, individual membership within voluntary associations increase trust in one's neighbours and that civic participation has beneficial consequences for the health of the entire community (Kunitz, 2004).

The findings in this study suggest a strong relationship between social capital and communication. Improved social capital may facilitate communication with people with learning disabilities with epilepsy and may lead to improved quality of life.

The advent of community living has brought about significant changes in the lives of people with learning disabilities who have long been denied access to community participation across Western Europe including the UK. They have been separated from their families leading to the diminishing of family bonds and social networks. Following the closure of long-stay mental health hospitals (British Asylums), the number of people with learning disabilities who are in

touch with primary care services have increased tremendously over the past one and half decades. The majority of these people have no established family links or social networks and may find it particularly difficult integrating and accessing community services. The existence of family bonds has been reported to facilitate communication. However, it is evident in this study that people with learning disabilities are still experiencing significant barriers in communicating and developing bonds in the community.

Society's perceptions regarding people with learning disabilities remain negative and impacting on quality of life. People with learning disabilities are faced with discrimination due to negative public perceptions regarding learning disabilities and epilepsy. Stigma regarding epilepsy has been reported in this study as a significant barrier to communication. It is argued that the way people with learning disabilities are perceived by others can be even more important to their ability to contribute to the development of social capital and their own social inclusion than their own disabilities (Bates and Davis, 2004). For example if people with learning disabilities are perceived as incapable of making a positive contribution to society it will limit their potential to develop reciprocal relationships with the general population in the community (Bates and Davis, 2004). In addition to empowering and building the individual service user's confidence, for example by reinforcing positive outcomes, there is need for public education regarding people with learning disabilities and epilepsy. Learning disability does not mean inability; therefore, offering lead roles and opportunities for service users may go a long way to empower people with learning disabilities. Also, education regarding the causes of epilepsy and treatment options available will be invaluable in reducing public perceptions regarding epilepsy. This may lead to improved quality of life for both the service user and the carer. Service users in this study view their involvement regarding health management as a civic right. They reported the need to have a stronger interpersonal relationship and egalitarian ethos with their health care professionals (Pilkington, 2002). Service users have

expressed concerns regarding the lack of involvement. They reported the need to be involved and participate in the management of their health, in particular, issues regarding changes to their medications.

Empowerment was reported by carers as a facilitator of communication. When individuals are empowered to take responsibility for their own health it leads to improved communication. Service users in this study reported the significance of developing and maintaining trusting relationships with health care professionals. Reciprocity of trust was viewed by service users to improve quality of life and enhance communication. In addition, service users reported familiarity with their health care providers as a factor that facilitates communication. Personality traits have been reported to influence communication in this study. Health and social care professionals who demonstrate humour, empathy and provide emotional supports were viewed by service users to facilitate communication and improved quality of life.

Moreover, in the voluntary sector, there are numerous epilepsy and learning disabilities organisations across the UK, such as Enable Scotland, Epilepsy Scotland and Epilepsy UK, which provide invaluable support for people with learning disabilities and epilepsy. These organisations make significant contribution by empowering people with epilepsy, for example through creations of jobs and employment, including campaigns to reduce stigma associated with learning disabilities and epilepsy, therefore enabling these people to contribute to society. The researcher suggests that building networks and communication with these organisations may lead to mutual benefits, in particular by sharing ideas and expertise regarding the provision of services including effective ways of communication for people with learning disabilities and epilepsy. This may lead to the development of stronger social capital and thus contribute to improved quality of life for people with learning disabilities and epilepsy.



## Chapter 7: Conclusions

### 7.1 Introduction

The last chapter discussed the findings that emerged from this study in relation to the project aim and objectives. The remit of the current chapter is to consider the study findings and draw overall conclusions for the study. It does this in relation to the study background and the objectives originally stated. Limitations or reservations inherent with this study will be discussed to inform the interpretations of the study findings and also for future replications or transferability. The chapter will conclude with recommendations for health policies, clinical practice, for education and for future research.

### 7.2 Overview of the need for this study

This study was triggered by the lack of research that investigated the views and experiences of people with learning disabilities regarding communication. The study aimed to bridge this gap by offering a listening ear and a voice for service users and carers to express their views and experiences of communication; for example regarding what constitutes effective communication and above all, how communication may be maximised.

#### *7.2.1 The originality of this study*

The originality of this study can be demonstrated by:

- the lack of research on communication with people with learning disabilities and an enduring condition such as epilepsy. To the best of the researcher's knowledge to date, there is not a single paper that looks at similar aspects as this project.
- studies regarding communication with people with learning disabilities usually focus on carers' and staff views regarding communication, together with their development needs regarding communication skills. This is to the neglect of the service users' views regarding communication.

- studies within the general population regarding service users' perspectives of epilepsy do not distinguish between the learning disabilities and the non-learning disabilities populations and thus the views of the learning disabilities population perceived needs are either neglected or subsumed within the general population.
- the majority of research in the general population regarding communication is devoted to children, but their modes of communication and needs are different from those of adults.
- communication studies regarding adults with learning disabilities are usually focused on institutionally-based individuals involving people with severe to profound learning disabilities, but little is known regarding community-based individuals who may have different communication needs and expectations.
- The majority of these studies adopt post-positivist methodologies and employ observational methods by means of video-recording and quantification of the frequency of verbal and non-verbal communication 'acts'; however, the individuals' views and perspectives regarding communication remain unsolicited.

The objectives set out to investigate in this study include: determine how people with learning disabilities and epilepsy communicate with their carers and health care professional regarding epilepsy and related issues; explore the strategies used by carers to communicate with people with learning disabilities; determine carers' perceptions of how people with learning disabilities and epilepsy communicate with health care professionals; and make recommendations on strategies which could be employed by people with learning disabilities, carers and health care professionals to facilitate communication regarding key issues such as seizure management and concordance with medications.

All of these objectives have been achieved as presented and discussed in the last two chapters respectively. The next section will draw these findings together and conclude this study.

### 7.2.2 Key findings of the study

Service users and carers have reported multiple and diverse views and experiences regarding communication. The study yielded six main themes as key findings that address the study objectives as shown in the figure below.

Figure III: Main findings of the study (duplicate of Figure III p.176)



The study revealed that service users are highly insightful regarding their communication with carers and health care professionals. In particular, service users in this study are well aware of their communication needs and expectations with carers and health care professionals.

#### *Communication needs and expectations*

The findings in this study show that service users have specific communication needs with carers and health care professionals, however, these communication needs are largely unmet. Particular

concerns expressed by service users in this study related to the lack of involvement in the management of their health needs by some health care professionals. Another concern expressed by service users related to a perceived lack of honesty of health care professionals. Service users in this study expressed their dissatisfaction regarding decisions about their health not being discussed with them but being concealed or withheld from them. Service users reported the value of having honest and open discussion with health care professionals. Another significant finding in this study related to trust and credibility. Service users reported lack of trust and credibility with health care professionals. This perception was compounded following medication errors by some health care professionals. However, trust as reported here appears to be reciprocal. Although service users reported lack of trust **in** health care professionals, they also had the perception that they are not being trusted **by** health care professionals, especially when reporting health issues such as side effects of medications. These findings reflect the need for developing and maintaining trusting relationships between service users and health care professionals.

*Engagement e.g. listening and sharing of information*

Furthermore, service users and carers in this study perceived 'engagement' as a predictor of effective communication. However, their experiences of engagement with health care professionals were perceived as primarily negative. Particular concerns related to: lack of time; poor listening and understanding and the quality and quantity of information provision. Service users and carers expressed the need to have more therapeutic time to engage face-to-face with health professionals. This view was supported by carers who reported the need for sufficient time to engage with health care professionals. Both service users and carers reported that some health care professionals are not interested, or do not make adequate time to listen to them. Service users are more likely to be involved and contribute to the consultation if sufficient time is made available and

the encounter is not rushed. In addition, service users perceived the quality and quantity of the information provision by some health care professionals to be poor. They reported the need for detailed information regarding health and related matters, where they can input rather than being told what to do.

Overall, these findings reflect the dominance of the medical models of communication employed by some health care professionals in clinical practice. Despite the numerous social policies geared towards consumer involvement in the provision and delivery of health services such as *'The same as you?'* A review of services for people with learning disabilities, (Scottish Executives, 2000); *Partnership for care*, (Scottish Executives,2003); *Valuing People Now: A new three-year strategy for people with learning disabilities* (Department of Health, 2009), the findings in this study suggest that service users in particular, are yet to experience the impact of these policies. The findings reflect the continuous medicalization of health services. It appears that service users in this study perceived health care professionals, in particular some doctors, to be too dictatorial regarding their health needs. They perceived the communication encounter to be directive and dominated by the health care professionals but the service users as consumers of health services contribute very little to the encounter.

### *Strategies for communication*

The findings of this study indicated that service users have good insight regarding their communication with carers and health care professionals. It was evident in this study that people with learning disabilities are not only passive recipients who depend solely on their carers to provide their communication needs. They are actively involved, and make determined efforts by adopting specific strategies to enhance the communication encounter. Service users' and carers' in this study have reported specific communication strategies they employ in order to remediate and compensate for any communication

deficits. A particularly significant finding here related to service users' and carers' reflective use of specific behaviours such as intimidation and assertiveness as strategies to effect communication with health care professionals.

### *Communication methods*

Service users and carers reported they communicate primarily by verbal methods in this study. The use of non-verbal forms of communication was mentioned albeit, to a very limited extent. However, it is clear from the literature that human communications are largely non-verbal. It remains unclear how much non-verbal forms of communications in this study are not reported or unrecognised, for example regarding body language. The use of augmentative and alternative methods of communication such as pictures and photographs has been extensively applied in the general population. Picture and photographs are particularly useful for people with learning disabilities who demonstrate a level of cognitive impairment. However, the use of pictures and photographs were reported to be lacking by one service user in this study. The lack of alternative and augmentative communication methods in this study appears to be linked with carers' knowledge and skills. One carer reported her lack of knowledge regarding non-verbal communication methods such as sign language. This may have implications for carer education and communication training needs as discussed in the previous chapter.

### *Factors that facilitate communication*

Furthermore, it was evident in this study that both service users and carers are able to evaluate the effectiveness of their communication by identifying factors that may facilitate the communication encounter. This is a further demonstration that service users are insightful regarding communication and yet their views regarding communication until this study have not been investigated. To a large extent, a significant number of the factors reported here relate to the characteristic of the individuals involved in the communication process

and the need for improved social capital for people with learning disabilities.

Facilitating factors described in this study include: first, communication is facilitated when there is the show of empathy and humour. Service users prefer health care professionals who demonstrate warmth and empathy. Humour was reported to play a role in communication. Being humorous creates an inviting and a stimulating atmosphere for communication and has been perceived to have a therapeutic effect. Second, it was also apparent that certain individual personality traits, including gender, appeared to facilitate communication. Third, the duration of the caring relationship allows the development of familiarity and the building of therapeutic relationships which enhance communication. Fourth, to a significant extent, specialist health professionals in learning disabilities and GPs with interest in learning disabilities were reported as good communicators. Finally, some service users reported the importance of using pictures and photographs to facilitate communication as it enhances recall and promote better understanding.

### *Barriers to communication*

Finally, it was also evident in this study that service users and carers are not only aware of factors that facilitate communication but are well aware of factors which are barriers to communication. These barriers appear to have different origins. Whilst some of these barriers are both external and internal in origin, such as stigma, epilepsy knowledge and information, and some carers' perceptions regarding people with learning disabilities, others appear to originate internally and relate to the individual service user's and carer's limitation.

Stigma is reported as a significant communication barrier in this study. Stigma is generally associated with reduced social interactions but manifested specifically as a barrier to communication in this

study. Service users reported that when people know that they have epilepsy they will not communicate with them. As a defence strategy, they conceal their epilepsy in order to promote social interaction and communication.

Another significant barrier to communication relates to carers' limited knowledge regarding epilepsy and related issues. Although carers reported they have limited roles regarding epilepsy and medication, both service users and carers acknowledged the need for carers to have basic knowledge and information regarding epilepsy. Some service users and carers perceived lack of knowledge and information regarding epilepsy as a barrier to communication. Sufficient knowledge and information regarding epilepsy will equip the carer to respond to basic needs of the service user in the event of an emergency and will also facilitate information sharing with health care professionals.

Moreover, the value of having quality time with health care professionals was largely recognised by both service users and carers as a marker of the quality of the communication. However, this was reported to be lacking and therefore a significant barrier to communication. Other communication barriers that emerged in this include: service users' lack of vocabulary, the impact of the disability in impairing communication, lack of pictures and photographs to supplement communication.

## 7.3 Study limitations or reservations

### *7.3.1 Introduction*

This study has some reservations or shortcomings which need to be considered when interpreting the findings to inform possible applications. Possible limitations in this study relate to the researcher and the study design and these will be discussed in this section.



### *7.3.2 Limitations associated with the researcher*

It is important to acknowledge that the researcher is not a native of the study locality and his background experiences and values have the potential to influence the interpretations of the data. All interviews were taped and transcribed verbatim. In addition, every care was taken to minimize the researcher effect on the data by verifying meanings and interpretations for agreements. All the analytical processes were clearly spelt out to allow external auditing of the analytical rigour of the study.

### *7.3.3 Limitations associated with the study design*

A significant factor for consideration in this study is that participants were recruited from a very small locality in Scotland through the local Managed Clinical Network for Epilepsy (MCN). Although issues relating to sampling and sample size have been discussed earlier in chapter 3, only 28 people were interviewed for this study. Also, only four carer communication diaries were administered. Therefore these findings may not be transferable to the entire population of Scotland. It is possible that a larger sample encompassing a wider geographical spread would have revealed phenomena that may not have been captured in this study.

Particular care should also be taken in terms of cross-cultural application because values, beliefs and experiences are ingrained in the local culture. The study investigates patients' views and experiences regarding health communication. However, the advent of consumerism in health services in general is influenced both by the local and national health policies which may not be applicable in other cultures or settings.

Also, this study focused exclusively on service users' and carers' views and experiences regarding communication. However, the views of health care professionals regarding communication with service users and carers would have added more depth and richness to the study

findings by considering the triads. However, this study will make a significant contribution due to the dearth of studies that access service users' views and experiences regarding communication.

Furthermore, only people with mild learning disabilities were sampled for this study and therefore the findings may not reflect the entire learning disabilities population due to variations in cognitive impairment and communication difficulty.

It is also worth noting that in terms of service user and carer relationships, the majority interviewed were care workers. It was evident in the findings that family carers' experiences of phenomena were different due to differences in relationships and expectations. Therefore, if a larger sample of family carers were interviewed for this study it may have illuminated more in-depth experiences of communication.

Moreover, the actual ages of participants were not known for confidentiality and ethical considerations. However, comparative analysis by taking into account participants' demography would have been helpful in unearthing any hidden phenomena.

Furthermore, due to the pragmatic nature of this study the participants were recruited through health and social care professionals. Although this has potential for bias, steps were taken in the consent process that ensured that people participated willingly and autonomously.

Overall, although the findings in this study are credible, these limitations or reservations should be taken into consideration when interpreting the findings to fully understand the context and the extent to which they can be applied.

## 7.4 Contributions to knowledge

### *7.4.1 Introduction*

In addition to fulfilling the stated objectives, this study has also made significant contributions to knowledge in a number of ways. This section will discuss some of these.

### *7.4.2 Theoretical and empirical contributions*

This study investigated and contributed to the understanding of, in particular, service users' views and experiences of communication regarding epilepsy and related issues. These findings have not been reported previously. The study has offered a rare opportunity for people with learning disabilities and their carers to express their views and experiences of communication and also their perspectives regarding health care professionals' communication. The findings that emerged from the study will serve as a foundation for a communication resource for carers and health care professionals (see Appendix 11).

### *7.4.3 Methodological contribution*

This study adopts a qualitative approach by means of semi-structured interviews for service users and carers to express their views and experiences regarding communication. The study is based on the principle that the best way of knowing why people behave the way they do is to ask them. Previous studies largely employ post-positivist or quantitative methodologies and neglect the service users' views and experiences.

Diaries have been widely used to collect health information previously, but little is known regarding communication diaries when used to communicate issues regarding communication. Solicited carer communication diaries were successfully utilized in this study and enabled carers to reflect and report on outcomes of their communications with service users. This yielded valuable findings that

overall, endorsed the credibility of the findings of the carers' interview data.

#### *7.4.4 Practical contributions*

This study is an exploratory study and has provided a range of descriptive findings regarding communication. The study has contributed to knowledge by furthering our understanding regarding the complexities of communication in particular, with people with learning disabilities and epilepsy. The findings that emerged from the study may serve as a useful resource for carers and health care professionals in clinical practice (see Appendix 11).

### 7.5 Recommendations

#### *7.5.1 Policies*

This study is an exploratory study; it is unclear whether these findings will have any immediate impact on health policies. As mentioned in the discussion chapter, policy outcomes are dependent on a range of factors and it may be premature to draw any conclusions regarding health policies based on the findings of this single study. The findings here suggest the need for more health policy research to investigate how relevant health policies reflect clinical practice.

#### *7.5.2 Clinical practice*

This study suggests that effective communication with people with learning disabilities is akin to a reflective model as described (see Appendix 11). There is a need to provide training to fulfil the needs of health and social care professionals regarding communication, and carers regarding epilepsy.

Overall, this study further suggests that improved social capital may enhance communication and lead to improved quality of life.

### *7.5.3 Education*

The study demonstrates that communication with people with learning disabilities is complex and challenging as discussed earlier. The researcher suggests that communication with people with learning disabilities should be made a compulsory content for all pre-registration health and social care education.

### *7.5.4 Further research*

Further research is needed encompassing a wider geographical spread to consolidate these findings by ascertaining the prevalence of the issues raised in this study across Scotland. Also, to ascertain health care professionals' views and experiences of communication with people with learning disabilities and epilepsy to inform the direction for policy formulations and implementations based on the triads.

The findings of this study are mainly descriptive. Therefore, there is a need to further investigate each of the main themes that emerged in this study, to gain a more in-depth understanding of the phenomena described by participants.

Future research could investigate how demographic variables such as age and gender may influence communication. The differences in experience reported in this study between multiple care workers and family carers also requires further research.

Also, the reflective model that emerged from this study needs to be further developed and tested.

Finally, future research should adopt either a participatory or emancipatory approach and involve people with learning disabilities in the design of the study. This may illuminate findings that are not captured in the current study and add to the rigour of investigation.

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## 9. Appendices

### Appendix 1. Information for health and social care professionals

|   |   |   |
|---|---|---|
|  | <b>Identification of effective methods of communication for people with learning disabilities and epilepsy and their carers</b> |  |
|---|---|---|

## Information for health and social care professionals

### Study title

Identification of effective methods of communication for people with learning disabilities and epilepsy and their carers

### Invitation

You are being invited to take part in a research study. 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. Take time to decide whether you wish to take part. Thank you for reading this.

### What is the purpose of the study?

This research is being done in order to identify effective methods of communication between people with learning disabilities and epilepsy and their carers. The study will be written up by the researcher (Jerry

Ninnoni) for submission for the award of doctor of philosophy (PhD). The long term aim is to improve the quality of life for people with learning disabilities and epilepsy and their carers.

### **Why have I been chosen?**

You have been selected to take part in the study because you provide care, support and/or treatment for people with learning disabilities and epilepsy and/or their carer.

### **Do I have to take part?**

No, taking part is voluntary. If you would prefer not to take part you do not have to give a reason. If you take part but later change your mind you can withdraw at any time. We will not proceed unless we have your consent.

### **What will happen if I take part?**

We would like you to participate in a focus group. This would be to comment on key communication issues identified from the study. This involved interviews and observation sessions with people with learning disabilities and their carers. We would like you to consider the implications for practice. Focus groups will be held in a convenient location and should be of approximately 60 minutes duration. Ten to 12 people will be included in a group and we would like to audiotape the discussion, if this is acceptable to all participants. All tapes will be wiped once transcribed. The discussion should last approximately 60 minutes.

### **What are the possible benefits of taking part?**

There may not be any direct benefits to you but you may feel that our study could help inform your practice. We also intend that information

obtained from the research may help improve the quality of life for people with learning disabilities and epilepsy and their carers.

### **Will my taking part in this study be kept confidential?**

Yes, all information which is collected during the course of the research will be kept strictly confidential. On all research documents your name will be removed so that you cannot be recognised from it.

### **What will happen to the results of the research study?**

We intend to inform people of the results through meetings, short written reports, talks at epilepsy meetings and articles in journals. We will ensure that nobody will be identifiable in any reports or publications.

### **Who is organising and funding this research?**

The Robert Gordon University is funding the postgraduate studentship. The project is supported by the North of Scotland Managed Clinical Network for Epilepsy.

### **Who has reviewed the study?**

The Grampian Research Ethics Committee has reviewed and approved this study.

### **Contact for further information**

#### **Mr Jerry Ninnoni**

Health Services Research Group



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## Appendix 2. Information for service users

|   |   |   |
|---|---|---|
|  | <b>Identification of effective methods of communication for people with learning disabilities and epilepsy and their carers</b> |  |
|---|---|---|

### **Information for people who take part.**

#### **Study title**

Finding out the best ways of talking to people and listening to them about your epilepsy.

#### **Invitation**

We would like you to take part in a study. We want to find out how you tell people about your epilepsy and how they tell you what they think. Before you decide please read this sheet.

#### **Why are we doing this project?**

We want to find out the best ways of talking about fits (epilepsy). This project will be written up by the researcher (Jerry) for a research degree (Ph.D). In the future we hope the research will lead to people knowing more about your epilepsy

#### **Why have I been chosen?**

You have been asked to take part because staffs think you would like to be in the study.

#### **Do I have to take part?**

No. You can choose whether you want to say yes or no. You do not have to say why. If you do take part, but then change your mind, the interview will stop.

#### **What will happen to me if I take part?**

We will ask you about how you talk with your carers about your epilepsy. This may take about 45 minutes. If you agree, we may tape record the talking, so that we can be sure what is said.

The tapes will be kept safe and private. They will be wiped after we have listened to them. You can decide where you want to talk to the researcher.

**What might I not like about taking part?**

You can ask someone you trust to be with you when you talk to Jerry in case you get upset. We can offer to pay your expenses.

**Will my taking part be confidential?**

Yes. Anything you tell us will be used without using your name. We will not use your name if we share anything you tell us.

**What will happen to the results of the research study?**

We will send you a short report and invite you to a meeting.

**Who is organising and funding this research?**

The Robert Gordon University is giving the money for this project. The North of Scotland Managed Clinical Network for Epilepsy is supporting this research.

**Who has checked this study?**

The Grampian Research Ethics Committee has reviewed and approved this study.

**For further information contact:**

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Email: [j.p.k.ninnoni@rgu.ac.uk](mailto:j.p.k.ninnoni@rgu.ac.uk)

**Thank you for agreeing to take part in the study.**

Appendix 3. Service users' consent form

**Consent by service user to take part in the project on communication with people with learning disabilities with epilepsy and their carers**



**Researcher: Jerry Ninnoni.**

|   |   |
|---|---|
|    | <p><b>I have seen the information sheet for the project. This has been explained to me.</b></p> <p><b>I've had the chance to speak with Jerry and ask him questions.</b></p>                  |
|    | <p><b>I agree to take part in the study, and know that I can change my mind and pull out at any time. This will be OK.</b></p>  |
|   | <p><b>I agree to talking with Jerry about the project and to the talking being taped.</b></p>   |
|  | <p><b>I know that later on I can ask for anything I've said to be taken out of the tape recording.</b></p>  |
|  | <p><b>I understand that this study is about finding out ways of communicating (talking and listening) with my carers and health and social care professionals e.g. doctors and nurses</b></p> |
|  | <p><b>I decided myself to take part in the study which I was told about.</b></p>  |

Signature of service user \_\_\_\_\_ Date: \_\_\_\_\_



## Appendix 4. Information for carers

|   |   |   |
|---|---|---|
|  | <b>Identification of effective methods of communication for people with learning disabilities and epilepsy and their carers</b> |  |
|---|---|---|

### Information for carers

#### Study title

Identification of effective methods of communication for people with learning disabilities and epilepsy and their carers

#### Invitation

You are being invited to take part in a research study. 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. Take time to decide whether you wish to take part. Thank you for reading this.

#### What is the purpose of the study?

This research is being done to identify effective methods of communication for people with learning disabilities and epilepsy and their carers. The entire study will be written up by the researcher (Jerry Ninnoni) for submission for the award of doctor of philosophy (PhD). The long term aim is to improve the quality of life for people with a learning disability and epilepsy and their carers.

#### Why have I been chosen?

Carers play a key role in supporting people with learning disabilities so that we would like to know your views on issues relating to

communication, especially with regard to epilepsy. We are inviting, in total, 25 carers caring from people with learning disabilities and epilepsy to take part in the study.

### **Do I have to take part?**

No, taking part is voluntary. If you would prefer not to take part you do not have to give a reason. If you take part but later change your mind you can withdraw at any time. We will not proceed unless we have your consent.

### **What will happen to me if I take part?**

We would like you to take part in an interview, lasting approximately 45 minutes. This can be held at a venue selected by you, it could be your own home, a private room at a carers centre or at the university. You will be interviewed by Jerry Ninnoni who has received training as an interviewer.

At the interview you will be asked to answer a number of questions (approximately 10) about communicating with the person you care for and especially about issues relating to epilepsy. You can choose not to answer any of the questions and may stop the interview at any point. We will ask for your consent to tape record the interview but it can still go ahead if you choose not to have it recorded. You may stop recording at any point in the interview. After the recording has been typed up the tape will be wiped.

After the interview you will be asked if you are willing to keep a diary for 14 to 21 days. We will provide the diaries with an entry for each day. We would like you to make diary entries regarding critical incidents, this might relate to a seizure or to a missed medication.

You will be asked after the interview if you would be willing to be observed communicating with the person you are caring for. We are

seeking to recruit 10 carers and the people they care for (10 pairs). Observation will take place 14 to 28 days after the interview, at a time convenient to you and the person you care for and if acceptable in your own home. If you prefer this could be in another venue chosen by you. We would like to use a fixed camcorder for recording purposes but an alternative method of recording communication could be used. The researcher (the same person who undertook the interviews) will spend 60 minutes in total with you (30 minutes of observation and 30 minutes to allow for any questions or queries on your part).

We will meet any reasonable expenses (such as travel costs) associated with your taking part. Reimbursement will be on the most economical form of transport and receipts will be required.

**What are the possible disadvantages of taking part?**

It is possible in some rare cases that you might feel upset in talking about your experiences. If you find any aspects of participation upsetting we will not continue with the interview. If appropriate we will provide information on possible sources of support.

**What are the possible benefits of taking part?**

We cannot promise the study will help you but the information we get from it should help improve the quality of life for people with learning disabilities and epilepsy and their carers. Also you may find it of benefit to talk to someone about your everyday experiences of living with someone with learning disabilities and epilepsy. The findings from the study may be used also  
to inform health and social care professionals' practice

**Will my taking part in this study be kept confidential?**

Yes, all information which is collected during the course of the research will be kept strictly confidential. On all research documents your name will be removed so that you cannot be recognised from it.

**What will happen to the results of the research study?**

We intend to inform people of the results through meetings, short written reports, talks at epilepsy meetings and articles in journals. We will ensure that nobody will be identifiable in any reports or publications.

**Who is organising and funding this research?**

The Robert Gordon University is funding this research. The project is supported by the North of Scotland Managed Clinical Network for Epilepsy.

**Who has reviewed the study?**

The Grampian Research Ethics Committee has reviewed and approved this study.

**Contact for further information****Mr Jerry Ninnoni**

Health Services Research Group

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Email: [j.p.k.ninnoni@rgu.ac.uk](mailto:j.p.k.ninnoni@rgu.ac.uk)

**Thank you for agreeing to take part in the study.**

**Appendix 5. Consent form for carers**

**Communication and people with learning disabilities and epilepsy and their carers**

- |  |                          |                          |
|--|--------------------------|--------------------------|
| 1. I confirm that I have read and understood the information sheet dated 18/05/07 (version 3) for the above study and have had the opportunity to ask questions. | <b>Yes</b>               | <b>No</b>                |
|  | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason  | <b>Yes</b>               | <b>No</b>                |
|  | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. I agree to the interview being audio-taped and am aware that audio-taping may be stopped at any time.   | <b>Yes</b>               | <b>No</b>                |
|  | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I also agree to the camcorder taping of the observation and that recording may be stopped at any time.  | <b>Yes</b>               | <b>No</b>                |
|  | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. I agree to complete a diary for a 14 to 21 day period   | <b>Yes</b>               | <b>No</b>                |
|  | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I agree to being observed for one 60 minutes session  | <b>Yes</b>               | <b>No</b>                |
|  | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. I agree to take part in the study   | <b>Yes</b>               | <b>No</b>                |
|  | <input type="checkbox"/> | <input type="checkbox"/> |

\_\_\_\_\_

Name of Participant

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

\_\_\_\_\_

Researcher



\_\_\_\_\_

Date

\_\_\_\_\_

Signature

## Appendix 6. Carer diary information

|   |   |   |
|---|---|---|
|  | <b>Identification of effective methods of communication for people with learning disabilities and epilepsy and their carers</b> |  |
|---|---|---|

### Carer diary information

Dear Carer,

Many thanks for agreeing to take part in this study. For the next two weeks, I would like you to keep a diary of how you communicate or talk with the person you are caring for. Please, take time to read the following information carefully and discuss it with others if you wish. Ask me or your nurses if there is anything that is not clear or if you would like more information.

Thank you for reading this.

#### **What is the diary about?**

The diary is about how you communicate/talk with the person you are caring for on daily basis. In order to do this, it would be best for you to identify an activity or event that you normally do with the person and tell us what you think about how you talk/communicate with him or her. Our main interest is in learning how your communication helps or does not help in doing the activity.

#### **Why do we need this information?**

We learn from our experiences. We want to learn about best ways of communication. For example talking and listening to the person you are caring for. We want you to share with us what kinds of talking or communication you think helps and what does not help in doing the activity.

The findings from the diaries may be used also to inform health and social care professional practice.

**What am I supposed to do?**

All you need to do is identify **one** routine activity/event from each of the three categories described below. Alternatively you could add your own activity if you prefer and then answer the questions under each of them.

Please, don't worry about your hand writing, spelling or grammar. We only want to understand what you think about how you communicate or talk with the person during the activity. Please, also take note of and record any non-verbal forms of communication during this activity. For example, gestures, body posture, head nodding, facial expression etc.

**Will my taking part be kept confidential?**

Yes, all information which is collected during the course of the research will be kept strictly confidential. On all research documents all names would be removed so that you cannot be recognised from it.

**Do I have to take part?**

No, your taking part to keep the diary is voluntary. If you would prefer not to take part you do not have to give a reason. If you take part and later change your mind you can withdraw at any time. We would not proceed until we have your consent.

**How long do I have to keep the diary?**

The diary is for just two weeks (14days), so think about these activities/events over the next two weeks and write about them in this diary as they occur

Thank you in anticipation for your help.

For any questions or clarification please contact:

Mr Jerry Ninnoni

Faculty of Health and Social Care

The Robert Gordon University

Garthdee Road, Aberdeen, AB10 7QG

Tel: 01224 263223. Fax: 01224 263042

Email: [j.p.k.ninnoni@rgu.ac.uk](mailto:j.p.k.ninnoni@rgu.ac.uk)

## **Appendix 7. Interview schedule for service users**

*Preliminaries: introduction/check personal details/assurance of confidentiality. Find out who they see as their carer if more than one carer, also identify the other carers.*

- 1a) How do you *communicate (talk)* with (establish name/s and use during interview) e.g. by using your voice or by pictures, signs, symbols pictures like these?
- 1b) How does he/she *communicate (talk)* with you? By using voice or by using signs and pictures like these?
- 2a) What kind of things do you talk about with him/her? *medication or epilepsy? Anything else? If you woke up and not feeling well will you tell someone? Who?*
- 2b) Do you talk to him/her the same kind of ways you talk to your friends?
- 3a) what does he/she do to let you know what he is talking about? *Point things out to you, say it in a different way or show you a picture in a magazine?*
- 3b) Is it easy/hard to know what he/she is talking about?
- 3c) What are the reasons for any *communication* difficulties? For example, are they about feelings or anxieties, hearing, memory or physical difficulties for example with getting the word out?
- 4) Do you get the chance to say what you think?
- 5a) Are there any issues/things you find difficult/hard talking about? *Or discussion with her? For example about epilepsy/seizures, medicines or stigma?*
- 5b) How do people treat you if they know you have epilepsy? *Do they treat you differently?*
- 6a) Does he/she/they understand/know epilepsy?
- 6b) Does she understand that you need to take your medicine?
- 6c) In the last two weeks, have you talked about or discussed epilepsy medicines?  
*What have you talked about?*
- 7a) Do you think he/she (they) listen to you?
- 7b) Does he/she (they) understand and take on board what you want to say? *Agree with you?*



- 7c) How do you know that they agree with what you say? *Does she do what you tell her to do?*
- 8a) How well do staff (doctors and nurses) talk to you? Are they good at talking to you?
- 8b) How well do they listen to you? Are they good at listening to you?
- 8c) Do you get the chance to say what you think?
- 9a) Do you think *communication/talking* problems affect what you do? Does it worry you?
- 9b) Do you think *communication/talking* makes a difference the way you are cared for? In which ways? *Are you happy with the way you talk with each other?*
- 10) Do you have any other comments you would like to make or add? *If you have a message what will it be?*

*Thank you*

*Version2-16/09/07*

## **Appendix 8. Interview schedule for carers**

*Preliminaries: introduction/check personal details/assurance of confidentiality. Establish whether paid or unpaid (relative carers). Find out who else cares for him/her and if he/she cares for another person.*

- 1a) How do you *communicate* with the person you are caring for? (*establish name and use during interview*) words, signs and photographs like these?
- 1b) How does he/she *communicate* with you? *E.g. by voice, Signs/board makers or photographs?*
- 2a) What kind of things do you normally talk about? *If she woke up and she not feeling well will she tell you?*
- 2b) Do you talk to him/her the same way you talk to your friends?
- 3a) What *communication* skills does he/she have? *What does she do to let you know what she is talking about?*
- 3b) Are there any particular *communication* difficulties? Is it easy/hard to understand him/her?
- 3c) What are the reasons for *communication* difficulties? For example, do they relate to feelings or anxieties, memory or learning problems or physical difficulties for example with getting the words out?
- 4) Does he/she get the opportunity to express his/her views?
- 5) Are there any things you find difficult *communicating* or discussing? *For example about seizures, medication or stigma?*
- 6a) Does he/she understand fits/seizures/epilepsy?
- 6b) Does she understand the need to take his/her medicines?
- 6c) In the last two weeks, have you talked about his/her fits/seizures/epilepsy medication?

- 7a) Do you think he/she listens to you?
- 7b) Does he/she understand and take on board what you talk about?
- 7c) How do you know that he/she takes on board?
- 8a) What is your opinion about the quality of communication by health and social care professionals such as doctors and nurses? *Are they good at communicating with you?*
- 8b) Do you think they listen to you?
- 8c) Do you get the chance to express your views?
- 9a) Do you think communication issues have any impact on your quality of life?
- 9b) Do you think it impacts on the person you care for? *In which ways?*
- 10) Do you have any other comments you would like to make or add? *If you have a message what will it be?*

*Thank you*

*Version2-16/09/07*

## Appendix 9. Sample diary

Your name:

Gender: M/F

Name of the person you are caring for:

Gender: M/F

What is your relationship with the person you are caring for? For example, key worker, husband, wife, partner etc.

How do you usually communicate with him/her e.g. verbal, non-verbal or both?

Please, identify **one** activity/event from each of the three categories for example, a **routine planning, domestic chores or health management** and answer questions under each of the categories.

**Category 1: Routine planning:** Please, identify an activity/event that you plan with the person you care for, for example, budgeting/finances, shopping or preparing a shopping list etc.

a) What did you do in this activity/event? How did you put across your message/ideas during this planning activity?

b) What kind of communication helped this to be a good experience that worked well?

c) What aspects of communication didn't work well?

d) Did you learn anything about how you and the person you are caring for communicate during this activity?

e) Would you try to communicate differently if you were to do the same kind of activity again? If so how?

Date and time of the activity:

**Category 2: Domestic chores:** Please, identify a household activity/event, for example, cooking, laundry, cleaning etc

a) What did you do in this activity/event? How did you put across your message/ideas during this planning activity?

b) What kind of communication helped this to be a good experience that worked well?

c) What aspects of communication strategy didn't work well?

d) Did you learn anything about how you and your client communicate during this activity?

e) Would you try to communicate differently if you were to do the same kind of activity again? If so how?

Date and time of the activity:

**Category 3: Health management:** Please, identify a health related activity/event, for example, taking medication, or refusal of medication, healthy eating, exercising, etc

a) What did you do in this activity/event? How did you put across your message/ideas during this planning activity?

b) What kind of communication helped this to be a good experience that worked well?

c) What aspects of communication strategy didn't work well?

d) Did you learn anything about how you and your client communicate during this activity?

e) Would you try to communicate differently if you were to do the same kind of activity again? If so how?

Date and time of the activity:

### Appendix 10. Participants' characteristics

| <b>Characteristics of service users</b>           |        |                    |                         |  |                                     |
|---|--------|--------------------|-------------------------|--|-------------------------------------|
| Service user code                                 | Gender | Interview location | Relationship with carer | Number of carers/care workers; level of support provided | Nature of reported epilepsy control |
| PA  | F      | Daycentre          | Service user/daughter   | One; daily support including appointments                | Good control                        |
| PC  | F      | Daycentre          | Service user            | Two; Cooking, shopping and appointments.                 | Good control                        |
| PE  | M      | Home               | Service user/husband    | One; general domestic family supports                    | Good control                        |
| PG  | M      | GP Surgery         | Service user            | One; twice weekly with Shopping and appointments         | Poor control                        |
| PI  | M      | Home               | Service user            | One; 4 days a week (domestic chores)                     | Good control                        |
| PK  | F      | Home               | Service user            | One; domestic chores and appointments                    | Poor control                        |
| PM  | M      | Home               | Service user            | One; domestic chores including financial advice          | Poor Control                        |
| PN  | F      | Home               | Service user            | One; domestic chores, financial advice                   | Good control                        |
| PP  | M      | Home               | Service user            | One; house chores and appointments                       | Poor control                        |
| PR  | F      | Home               | Service user/wife       | Daily family support and safety during seizure           | Poor control                        |
| PT  | F      | Home               | Service user            | Live in 24hr support accommodation                       | Good control                        |
| PV  | F      | Home               | Service user            | Live in a supported accommodation                        | Poor control                        |
| PX  | F      | Home               | Service user            | Live in a supported accommodation                        | Good control                        |
| PY  | M      | Home               | Service user/husband    | Live in a supported accommodation                        | Good control                        |
| PAa   | F      | Home               | Service user            | Live in a supported accommodation                        | Good control                        |
| <b>Characteristics of carers and care workers</b> |        |                    |                         |  |                                     |

| Carer/care worker code | Gender | Interview location | Relationship with service user/s | Number of service users; type and/or level of support provided | Amount of contact with user/s in this study |
|------------------------|--------|--------------------|----------------------------------|--|---|
| PB                     | F      | Daycentre          | Family carer                     | Daily family support   | (wife) daily support                        |
| PD                     | M      | Daycentre          | Care worker                      | 12; domestic chores and appointments                           | Daily support                               |
| PF                     | F      | Home               | Family carer                     | One; activities of living                                      | Daily support                               |
| PH                     | M      | GP Surgery         | Care worker                      | Seven; domestic chores and Appointments                        | 2 days per week                             |
| PJ                     | F      | Service user home  | Care worker                      | 15; domestic chores, help with finances                        | 4 days a week                               |
| PL                     | M      | Service user home  | Care worker                      | One; domestic chores and appointments                          | Daily support                               |
| PO                     | F      | Service user home  | Care worker                      | Five; domestic chores and appointments                         | Daily support                               |
| PQ                     | F      | Service user home  | Care worker                      | Four; domestic chores and social events                        | Two days per week.                          |
| PS                     | M      | Service user home  | Family carer                     | One; domestic chores and safety at home                        | Daily support                               |
| PU                     | M      | Service user home  | Care worker                      | Four; appointments and domestic chores                         | Average of 3days/week                       |
| PW                     | F      | Service user home  | Care worker                      | Four; appointments and social events                           | Average of 3days/week                       |
| PZ                     | F      | Service user home  | Family carer                     | One; domestic chores and social events                         | Average of 3days/week                       |
| PAb                    | F      | Service user home  | Care worker                      | One; general support with chores                               | Average of 3days/week                       |



## Appendix 11. Recommendations for practice

### Introduction

The findings in this study demonstrate the complexities of communication involving people with learning disabilities, especially when further compounded by the presence of an enduring condition such as epilepsy. Although the study focused exclusively on service users' and carers' views and experiences regarding communication nevertheless, the findings have strong potential to influence clinical practice as discussed earlier. What is crucially significant about this study is that the recommendations forwarded here are based on the service users and carers' views and lived experiences regarding communication with health care professionals, an aspect that has not been reported previously.

The findings suggest that effective communication with people with learning disabilities is akin to a reflective cycle of events (see figure Y) that requires carers and health care professional's self-assessment of the individuals' communication skills and needs prior to any communication encounter.

*Figure Y: Effective communication between health care professionals and service users and carers*



Relevant questions that resonate in the study findings as shown in the above figure include: What are service users' communication needs and

expectations? What are service users and carers' views and experiences of communication with health care professionals e.g. regarding how they 'engage' in a dialogue and exchange ideas and opinions with each other? Are there any communication strategies available? What is the best method of communication, verbal or alternative and augmentative methods or a combination of both? Are there any factors that can facilitate the communication process? Finally, anticipate communication barriers and adopt appropriate measures to remediate them.

The aim of this section is to make summarised recommendations regarding how the findings in this study may be translated into clinical practice. These recommendations reflect the main themes and sub-themes that emerged from the study as shown in the above figure.

### *Key recommendations*

#### 1. Service users' and carers' communication needs and expectations for health care professionals.

People with learning disabilities and epilepsy may have different communication needs and expectations of carers and health care professionals. Service users in this study reported the need for health care professionals to look beyond their conditions and involve them as individuals who are entitled to full information regarding their health management.

#### *Recommendations:*

- ❖ Build and maintain a trusting relationship with service users
- ❖ Involve service users and carers in all decision making processes including changes to medications
- ❖ Be open and honest with service users regarding medication changes
- ❖ Maintain consistent information regarding changes to medications with service users and carers

- ❖ Explore service users' psychosocial needs and provide support if possible
- ❖ Consider carers' and social care staff training needs regarding epilepsy and information in a format they can understand

## 2. Health care professionals 'engaging' with service users and carers

Service users and carers have strong insight regarding communication and can evaluate the effectiveness of the communication encounter. Service users in particular, have reported different expectations regarding communication with health care professionals and carers. In particular, service users expressed concerns regarding 'engaging' with health care professionals for example regarding the exchange of information. This involves listening, understanding and the quality of the information provision.

### *Recommendations:*

- ❖ Make sufficient time for the service user to express their views and needs
- ❖ Listen actively and encourage the exploration of service user's feelings.
- ❖ Be non-directive and adopt patient-centred communication approach
- ❖ Avoid dictatorship, be discursive and let service users understand their care and the management options available to them to inform their health decisions
- ❖ Use lay person's language and avoid medical terms
- ❖ Encourage the service user contributions to the discussion

## 3. Strategies of communication.

Service users and carers are aware and have reported a range of strategies perceived to enhance communication. These strategies may serve as an endorsement or a reflection of what already exist in clinical practice.

*Recommendations:*

- ❖ Consider the individual communication styles and adjust appropriately to meet the understanding of service user
- ❖ Recognise non-verbal communication such as behaviours including intimidation as possible forms of communication regarding the psychosocial impacts of epilepsy
- ❖ Plan the communication session e.g. identify a suitable communication environment and make sufficient time for the communication encounter
- ❖ Reinforce the message and check for understanding

#### 4. Methods of communication

A range of communication methods were reported in this study. Suggestions were also offered by service users regarding how communication may be enhanced.

*Recommendations:*

- ❖ Do not over rely on verbal communication consider non-verbal methods to enhance communication
- ❖ Consider alternative and augmentative communication methods e.g. signs, pictures and photographs to supplement verbal communication methods

#### 5. Factors that facilitate communication

Service users and carers in this study have also identified a range of factors perceived to facilitate communication.

*Recommendations:*

- ❖ Individualise the communication e.g. one-on-one sessions
- ❖ Use appropriate humour
- ❖ Use empathy
- ❖ Empower the service user by involving and offering roles, giving positive feedback and reinforcing positive outcomes
- ❖ Provide options for the service user to choose

- ❖ Use alternative augmentative communication methods e.g. pictures and photographs to supplement the spoken words
- ❖ Consider gender issues and respect service users' preferences.

## 6. Barriers to communication

Service users and carers have reported numerous factors acting as barriers to communication. It may be a good practice for health care professionals to always anticipate communication barriers, and assess known limitations that are inherent with the individual which are likely to act as barriers to communication prior to any encounter with the service user.

### *Recommendations:*

- ❖ Ensure adequate knowledge and information. Carers' lack of knowledge and information regarding epilepsy was perceived as a barrier to communication
- ❖ Educate and build service user confidence to minimize stigma regarding epilepsy
- ❖ Empowerment by setting goals and reinforcing positive outcomes
- ❖ Ensure sufficient time for service user to input in the communication
- ❖ Consider physical and cognitive impairments that may impact on the persons' ability to communicate
- ❖ Consider gender issues and respect the individuals preferences

Appendix 12. Extract from field notes

① 10/04/08.  
~~Student~~ student (female)  
a couple of days ago with  
cuts and stitches.  
appeared less in mood and  
shy. Had not offered as  
much as she should have  
Had another appointment  
today for a re dressing  
of wounds.  
Do not use any communi-  
cations signs or photography.  
A few distractions and  
interruptions by staff movements  
and phone ringing.  
Appared to like the use  
of photography as she  
was observed to be putting  
her hands on some of them.

Appendix 13. Extract from log book

09/09/07.

- check alerts on Zefoc  
to update literature.

Noted down 6 articles:

(1) Scheffer et al (2006).  
Do false predictions of seizure  
depend on the state of  
vigilance? A report from  
two seizure prediction methods &  
proposed remedies. *Epilepsia*  
Vol. 47 no 12 2058-2070.

(2) Drakmatopoulos et al (2006).  
A survey of public awareness  
understanding and attitudes  
towards Epilepsy in Greece.  
*Epilepsia* Vol. 47 no (12) 2154-2164

(3) H. Tris et al (2007). Sudden  
unexpected deaths in epilepsy  
& Search for risk factors.  
*Epilepsy & Behaviour*  
Vol (10) 138-141

(4) Raby L. K. (2007). 7  
adults with  
epilepsy -  
(10) 142-  
(5) Yaen et  
and Morbec  
in people  
stress park  
Epilepsy (1  
(6) Beghie  
disorders in  
47 Supp. 2  
- Sent an e  
Mennoc &  
Bettau can  
- Sent c  
have situ  
meeting for  
w/ epilepsy  
to be con  
- Email J  
Scottish C