The Experiences of Adults with a Learning Disability in Specialist Inpatient Assessment and Treatment Units

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ABSTRACT

UK Government policy advocates that as far as possible, adults with a learning disability should be supported within mainstream community settings (Department of Health, 1993; 2001; 2007). However, for individuals who present with mental health problems or exceptional challenging behaviour, admission to a specialist inpatient unit is sometimes necessary. Despite a growing body of literature exploring service users' views of community and healthcare services, research exploring their views and experiences of inpatient admission remains limited.

The aim of the current study was to address this gap in the literature by conducting a qualitative exploration of service users' experiences in specialist inpatient assessment and treatment units. The study employed a Grounded Theory methodology to obtain multiple perspectives on service users' experiences, using semi-structured interviews with service users, carers and staff members. Verbatim interview transcripts were analysed in line with the Grounded Theory approach to develop a rich and in-depth understanding of service users' experiences.

From the data analysed, five core concepts were constructed which provided a theoretical model for understanding service users' experiences of admission. This model proposes that service users' experiences can be understood in relation to procedural aspects of 'the course of admission' as well as the psychological processes 'sense of self and connectedness', 'sense of agency' and 'creating safety and protection' which contribute to the construction of 'understanding and meaning'. Findings are considered in relation to the existing literature and social constructionist, systemic and attachment theories.

Clinical and service development implications from the research findings highlight the need for inpatient staff to consider the impact of psychosocial factors and processes on service users' experiences, as well as the procedural aspects of admission. Recommendations are also made for maintaining family involvement, creating a context in which shared understandings between staff, carers and service users can be constructed, and developing links with community services.

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CHAPTER 1: INTRODUCTION

1.1 Chapter Overview

Recent Government policy has facilitated a change to the way in which adults with a learning disability who present with challenging behaviour or mental health problems are cared for (Department of Health, 1993, 2001, 2007). This has resulted in a shift from service users being accommodated in large, long-stay hospitals to being supported more and more within community settings. However, a small but significant proportion of these adults cannot be supported effectively by community services alone and often require inpatient admission. Three different models of inpatient services are utilised in the UK for adults with a learning disability.

Despite widespread call for service users' views on their experiences of the healthcare they receive, very little research has been undertaken exploring their opinions of inpatient admission. The current study therefore aimed to provide an insight into the experiences and views of adults with a learning disability who were admitted to specialist inpatient assessment and treatment units.

This chapter comprises four parts. In Part 1 key definitions are provided for terms used throughout the study and literature search. This is followed by a brief overview of the prevalence of challenging behaviour and mental health problems in people with a learning disability and a history of the development of learning disability services over the recent years. A description of the different inpatient service models is then provided with a discussion around the research and views on each of them. Part 2 introduces the issues surrounding the importance and challenges associated with obtaining service users' views. This is followed by a brief review of the literature reporting service users' views of community and healthcare services. Part 3 then provides a focused review of the literature relating specifically to service users' and carers' views and experiences of inpatient services. The scope of the literature search is explained and key aspects of the views of service users and their carers are discussed with consideration to the differences in experiences across service settings. This section concludes with an exploration of the limitations of the existing research. Part 4 summarises the rationale, aims and objectives of the study.

Part 1: Setting the Scene

1.2 Terminology

1.2.1 Learning Disability

Terminology within scientific and lay literature to describe people with a learning disability is broad. Many different terms are used interchangeably including *'learning disability' 'mental retardation,' 'learning difficulty,' 'intellectual disability,' 'mental handicap,'* and *'mental impairment'* yet often subtle differences exist between the meanings of these terms (Emerson, 2001). The researcher recognised the wide use of these generic terms and has therefore been guided by The British Psychological Society (BPS, 2000) in choosing the term '*people with a learning disability.'* The term *'service user'* will also be utilised to refer to people with a learning disability accessing services, as this terminology is commonly used.

1.2.2 Mental Health Problems

A number of terms including *'psychiatric disorder,' 'mental ill health,' 'mental disorder'* and *'mental health difficulties'* are also commonly found in the literature. The researcher has chosen to use the term '*mental health problems'* which is used by the service within which the research was undertaken and is favoured by MIND and The Mental Health Foundation.

1.2.3 Inpatient Services

The term *'inpatient service'* is used to describe any inpatient service to which adults with a learning disability may be admitted in order to receive support in relation to challenging behaviour and/or mental health problems. The term *'inpatient admission'* refers to any period of stay within such a service. Different models of inpatient service, including mainstream services provided within general adult mental health settings and services specific for adults with a learning disability, are described more fully in section 1.6.

1.3 Definitions

1.3.1 Learning Disability

Within the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10), the World Health Organisation defines '*mental retardation*' as:

> '*a condition of arrested or incomplete development of mind, which is especially characterised by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities.*' (World Health Organisation, 1992, pp.369)

Three core criteria are widely recognised as needing to be met in order for a person to be diagnosed as having a learning disability (World Health Organisation, 1992):

1. Significant impairment in intellectual functioning.
This is commonly assessed using an individually administered test of intelligence, such as the Weschler Adult Intelligence Scale (IV) (Weschler, 2008), which is sensitive in identifying an individual's level of ability in understanding new or complex information or in using new skills.

2. Significant impairment in adaptive/social functioning
This refers to a person's reduced conceptual, practical and social skills in comparison to that which would be expected within their culture. This often results in difficulties taking care of themselves and living independently; developing and maintaining social relationships; and keeping themselves safe.

3. Early onset (before adulthood)
The presence of impaired intellectual and adaptive/social functioning must have occurred during the developmental period of life i.e. in childhood before the age of 18 years. This criteria distinguishes people with a learning disability from those with acquired brain injury.

Individuals are diagnosed with varying degrees of disability namely mild, moderate, severe or profound dependent on their level of impairment. This classification system is used for

the purposes of identifying needs and providing access to appropriate services (Sturmey, 2007). Furthermore, access to services may also be influenced by the presence of additional difficulties such as challenging behaviour or mental health problems.

1.3.2 Challenging Behaviour

A definition that is widely cited proposes that challenging behaviour is *'culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit the use of, or result in the person being denied access to, ordinary community facilities'* (Emerson, 2001, pp.3).

The label of 'challenging behaviour' is descriptive rather than diagnostic however. It is widely acknowledged that challenging behaviour is a socially constructed phenomenon as it is largely dependent upon whether the behaviour is perceived to be challenging according to the culture and environment in which it occurs (Emerson, 2001). Accordingly, behaviour is only deemed challenging when it is defined this way by the context in which it occurs. There are a number of features which commonly result in a behaviour being viewed as challenging including when a behaviour is dangerous; interferes with a person's daily functioning or results in them being excluded from services; causes significant stress to others involved in providing support; or is problematic in itself given its duration, frequency and severity. Behaviours considered challenging therefore often include physical aggression towards others, self-injurious behaviours such as head hitting, self-biting, scratching, and destructiveness towards property (Allen, 2008).

1.3.3 Mental Health Problems

The World Health Organisation (WHO, 2001, pp.21) defines mental and behavioural disorders as *'clinically significant conditions characterized by alterations in thinking, mood (emotions) or behaviour associated with personal distress and/or impaired functioning.'* The nature and severity of mental health problems can range from day to day worries to severe and enduring problems such as recurrent depressive disorder, psychosis and bipolar affective disorder. Mental health problems can affect an individual's thoughts,

feelings and behaviours and may have wide ranging social and interpersonal consequences (The Mental Health Foundation).

1.4 Challenging Behaviour and Mental Health Problems in People with a Learning Disability

1.4.1 Prevalence Rates

It is evident from the definitions presented that challenging behaviour and mental health problems share a number of common features with both being identified by disturbances in behaviour as well as changes in cognitive and emotional states. Behaviours which are defined as challenging may therefore also be considered symptoms or expressions of mental health problems and vice versa. Due to these definitional limitations, it is difficult to accurately establish prevalence rates. Indeed it is argued that the reportedly high rates of mental health problems within this population may be attributable to the prevalence of challenging behaviour and its inclusion as a form of mental health problem (Allen, 2008; Allen & Davies, 2007).

Despite this ongoing debate however, there is now a wide consensus that people with a learning disability are at an increased risk of presenting with challenging behaviour and/or experiencing mental health problems, when compared to the general population, with prevalence rates as high as 97% reported depending upon inclusion criteria (Chaplin, 2011; Cooper *et al.,* 2007). Psychiatric morbidity in people with a learning disability has also been suggested to be 2-3 times higher than that in the general population (Alexander *et al.,* 2001).

Research has identified a number of factors which play a role in the increased risk of challenging behaviour and/or mental health problems in people with a learning disability. These include the severity of the learning disability; reduced activity, socialisation and opportunities for self-actualisation; life events such as placement break down and traumatic experiences; low self esteem; and insecure attachments (Allen, 2008; Allen & Davies, 2007; Martorell & Tsakanikos, 2008)

1.4.2 Consequences

The consequences of both challenging behaviour and mental health problems for people with a learning disability, their families and services around them can be significant. Such difficulties often include stress for the person with the learning disability and their carers; risk of service breakdown and social exclusion; use of out of area placements and significant costs to local authorities and health boards (Allen, 1999). It is unsurprising therefore that people with a learning disability are likely to require the support of specialist learning disability and/or mental health services which are specifically designed to meet their emotional and behavioural needs at some point during their life (Department of Health, 2009).

1.5 Development of Services

1.5.1 Social Role Valorisation and De-Institutionalisation

Services for people with a learning disability have undergone massive changes over the past few decades. These changes have been influenced by concerns regarding the accommodation of people with a learning disability in large institutional hospitals and by Social Role Valorisation theory (Cocks, 2001; Lemay, 1995; Wolfensberger, 1992). This theory, which has its origins in the principles of 'normalisation', proposes that people with a learning disability are socially devalued by the negative evaluations that society attributes to them. The strategic objective of Social Role Valorisation theory therefore is to enhance the competencies of people with a learning disability and improve their relationships with others in order promote the view that people with a learning disability are socially valued (Cocks, 2001; Wolfensberger, 1992).

In line with the aims of Social Role Valorisation, 'de-institutionalisation' represents a significant change in service provision for adults with a learning disability with the closure of long stay hospitals and the resettlement of residents into the community. Underpinning this move towards community living are beliefs that large institutional care settings resulted in the devaluation and disablement of people with a learning disability by society, social exclusion and isolation, and '*long-term incarceration ... [within] prisons of protection*' (Burrell & Trip, 2010, pp.176).

In 2001 the Department of Health issued the white paper '*Valuing People: A new strategy for learning disability for the 21ˢᵗ century'* (Department of Health, 2001) which outlined the UK strategy for the development of services for people with a learning disability. This strategy was based upon four core principles; rights, inclusion, choice and independence. At the same time the Welsh Learning Disability Advisory Group (2001) produced '*Fulfilling the Promises,'* which presented a similar framework for the development of learning disability services within Wales. Together, these strategy documents have been instrumental in outlining and developing UK wide services for people with a learning disability. Their emphasis has been on increasing the control service users have in making decisions regarding their lives; ensuring that the individual rights of service users are respected; and facilitating the active inclusion of service users in planning and evaluating the services they access.

The Mansell Report (Department of Health, 1993) also recommended that steps be taken to ensure the mental health needs of people with a learning disability were addressed through the provision of highly individualised, community based and locally provided services. UK Government policy also strongly advocates that people with a learning disability should be enabled to lead their lives in ways which reflect those of the general population – including having access to the same levels of service provision – and should not be unlawfully subject to deprivation of their liberty within hospital or residential care settings (Ministry of Justice, 2008).

1.5.2 The Need for Inpatient Services

De-institutionalisation and the drive towards community based mental health services for people with a learning disability have brought opportunities for many service users to access the same provisions as those available to the wider population. However, services remain somewhat limited and unevenly developed across the UK (Cumella, 2009; Hassiotis *et al.,* 2008; Holland, 2007). It is reported by Lyall and Kelly (2007) that a significant proportion of people with a learning disability living in the community will also require support in excess of that provided by community services, with a lack of such provision being linked with fatal consequences.

Furthermore, it is possible that the demand for specialist inpatient services will grow with the increased detention of people with a learning disability following the widening of the definition of 'mental disorder' in the recent amendment to the Mental Health Act (Department of Health, 2008). The introduction of the 'appropriate treatment' test within this amendment will also mean that individuals detained under the Mental Health Act, including people with a learning disability, will have to be detained in services which can meet their specialist needs (Hall & Ali, 2009; Picton, 2008).

In a study by Xenitidis *et al*. (2004), of those people with a learning disability already in contact with Community Learning Disability Mental Health Teams, 17% required some period of inpatient admission over a 3-year period. It is also estimated that between two and four acute inpatient beds are needed per 100,000 population (Alexander *et al*., 2001). The need for appropriate inpatient services to be provided in order to effectively meet the complex needs of this population is therefore highlighted.

1.6 Inpatient Service Models

It has been proposed that inpatient services for people with a learning disability should offer short term, highly focused assessment and treatment of challenging behaviour and mental health problems within the context of a wider care pathway (Department of Health, 2007). Three models of inpatient services are currently available within the UK to complement and support community services and are provided by both the public and private sector (Bouras & Holt, 2004; Cumella, 2009).

1.6.1 Mainstream

Within this model, inpatient care is provided within mainstream acute adult mental health wards and service users are supported by staff trained from within a generic adult mental health model (Chaplin *et al*., 2008).

1.6.2 Specialist

Short-term assessment and treatment in specialist inpatient services is provided in dedicated multi-disciplinary learning disability mental health units (Lyall & Kelly, 2007; Slevin *et al*., 2008). Staff within these services will have undergone learning disability

mental health training and have often received additional training specific to the needs of this population for example in challenging behaviour or communication support strategies. Specialist services are sometimes located some distance from people's homes or within purpose built units in the grounds of old long stay hospitals (Hall *et al.,* 2006; Mansell *et al.,* 2010; Trower, 1998).

1.6.3 Integrated

Integrated services have been developed in an attempt to provide specialist care within mainstream adult mental health settings. Such services consist of dedicated learning disability beds within mainstream acute adult mental health wards with staff from specialist services working in partnership with staff within mainstream wards. Services are developed and provided locally, crossing health and social care service boundaries (Hall *et al.,* 2006).

1.7 Which Model to Use?

1.7.1 Government Agenda

In line with the principles of de-institutionalisation and normalisation, UK Government policy advocates the use of mainstream adult mental health inpatient services (Department of Health, 1993; 2001; 2007). The Department of Health (2001, pp.66) states *'people with a learning disability should be enabled to access general psychiatric services whenever possible.'* However, it is recognised that mainstream services may require support from specialist learning disability services in order to achieve this (Department of Health, 2007). It is also acknowledged that specialist inpatient services may be necessary for people with severe challenging behaviour and *'for the small number of individuals with significant learning disabilities and mental health problems who cannot appropriately be admitted to general psychiatric services, even with specialist support'* (Department of Health, 2001, pp.67; 2007, 2009). The Royal College of Psychiatrists (2003) also supports the need for specialist inpatient services, highlighting concerns about the ability of mainstream adult mental health provision to appropriately meet the complex needs of service users.

1.7.2 Views on Different Service Provisions

There is a growing body of research examining the outcomes and effectiveness of different service models and proponents of each have argued for their benefits. However, there remains considerable debate regarding the proposed advantages and disadvantages of the different inpatient service models outlined above (Chaplin, 2004).

In line with government thinking, it has been argued that mainstream settings provide a more inclusive service for people with a learning disability which is less stigmatising than specialist service provision and more reflective of the principles of 'normalisation' (Bouras & Holt, 2004; Murphy *et al.,* 1996). Indeed, Blunden and Allen (1987) highlight that one of the concerns regarding specialist inpatient services may be the impact of labelling upon service users' self esteem. However, mainstream and integrated inpatient service models introduce the potential for increased vulnerability of this population (Hall *et al.,* 2006) and the lack of an appropriate peer group (Vos *et al.,* 2007). The claim that service users experience more inclusion in integrated inpatient services is challenged by findings that they are often located in separate areas or wards of the service and that feelings of isolation and rejection may in fact be exacerbated (Hall *et al.,* 2006). In contrast, the bringing together of service users with complex and varying needs on specialist units may increase challenging behaviour and it is argued that there is a lack of evidence for the benefits of locating people with a learning disability together (McKenzie, 2011). Furthermore, emergency admissions and the unpredictable nature of specialist inpatient units have been shown to monopolise staff time and disrupt the treatment of service users (Hoefkens & Allen, 1990).

Conflicting beliefs are highlighted within the literature with regards to the availability of services and the quality of care across settings. Whilst mainstream provision is seen to offer a wider range of services (Trower *et al.,* 1998), specialist services are seen to have staff with the necessary expertise to support people with a learning disability (McKenzie, 2011) and provide 'appropriate treatment' within the context of the Mental Health Act (Hall & Ali, 2009; Picton, 2008). It has been argued that mainstream services are unsuitable for people with a severe learning disability (Bailey & Cooper, 1997) and that staff in these services do not understand the communication issues, the complex social networks or the presentations of mental health and challenging behaviour in people with a

learning disability (Hall *et al.,* 2006; Trower *et al.,* 1998). Indeed, specialist services are often recognised for accepting referrals for service users with a wide range of learning disability and more complex needs (Cummella, 2009). It has also been proposed that as specialist inpatient units are specifically designed to meet the needs of this population, these environments may be better equipped and adapted to withstand the effects of challenging behaviour (Blunden & Allen, 1987).

Specialist inpatient services may also benefit from better access to community learning disability services (Chaplin, 2009) and these links may have a significant impact upon developing and delivering inpatient treatment packages whose gains can be maintained in the community (Murphy *et al.,* 1996; Newman & Emerson, 1991). However with specialist services often being out of area, maintaining community links can be a challenge for specialist inpatient services (Mansell *et al.,* 2010). Concerns have been raised that community services may see inpatient admission as an '*easy option'* (Blunden & Allen, 1987, pp.25) or as an opportunity to abandon responsibility for service users (Newman & Emerson, 1991), both of which are likely to hinder the development of competence within local services.

An additional challenge facing inpatient services is a general lack of community services, with research indicating that discharge from specialist services is hindered by this (Cummella, 2009; Lyall & Kelly, 2007; McKenzie, 2011) as well as by funding issues (Slevin *et al.,* 2008). This issue of 'bed blocking' (service users taking up or 'blocking' an inpatient bed because there is no community provision for them to go to) results in service users having longer admissions to specialist services, similar to those experienced before the closure of long stay hospitals, and remaining in hospital longer than necessary (Slevin *et al.,* 2008; Watts *et al.,* 2000). This is supported by findings that the average length of admission on mainstream units tends to be shorter (Chaplin, 2004; Hall *et al.,* 2006). Following a recent investigation into learning disability hospitals it has been found that specialist facilities, designed to provide short term assessment and treatment of ideally 3-6 months, have service users on them who have been there for up to 20 years. Concerns are therefore being raised about service users becoming 'imprisoned' and losing the valued and meaningful opportunities that were intended with de-institutionalisation (Pitt, 2011).

There is a lack of high quality research within this field however, with very few studies or randomised control trials directly comparing service models (Trower *et al.,* 1998; Chaplin, 2009). Furthermore, whilst outcome data such as referral rates, service use, length of admission and treatment outcomes across settings is beginning to be considered, research exploring the experiences and views of stakeholders, in particular those of service users, remains limited (Scior & Longo, 2005).

Part 2: Service Users' Views

1.8 Obtaining Service Users' Views

1.8.1 The Importance in Obtaining Service Users' Views

Service users have repeatedly expressed a desire to be included in research and to have their views heard and incorporated in the development and delivery of services (Owens *et al.,* 2008). The priorities of service users regarding research within mental health and learning disability contexts are similar to those of other stakeholders. Service users have identified a need for more investigation into their potential role in service planning and delivery; promotion of their independence, self-esteem and recovery; and issues relating to the quality of inpatient and residential care environments (Owens *et al.,* 2008).

Empowering service users to be more involved in their care and in service development and evaluation is high on the agenda of national and local policy with a particular push for the active inclusion of service users' views in the planning of healthcare provision (Department of Health, 2001). Given the increased prevalence of mental and physical health difficulties in adults with a learning disability, it seems crucial that their experiences in this area are understood. To restrict the involvement of those who are able to provide a unique insight into their experiences would seem unethical. It is widely recognised, however, that the views of individuals with a learning disability on the healthcare services they receive are still often overlooked (Department of Health, 2009; Royal College of Psychiatrists, 2003; Young & Chesson, 2006).

1.8.2 Challenges

Achieving service user involvement is hindered by a wealth of factors, many of which relate to the service contexts within which research is undertaken. Barriers such as negative staff perceptions regarding the contributions service users can make; service culture surrounding risk management; and beliefs about capacity to give consent can all result in the voices of service users, particularly those with a more severe learning disability or behavioural difficulties, not being heard (Arscott *et al.,* 1998; Chaplin *et al.,* 2009; Gorfin & McGlaughlin, 2005). In order to overcome these barriers staff and carers can provide valuable support to service users in expressing their views. This however, brings with it a number of further challenges. The presence of staff during interviews introduces the potential for bias as service users are more inclined towards offering responses which are seen as pleasing to staff (Young & Chesson, 2006). Furthermore, acquiescence is a potential obstacle for researchers to overcome, although evidence points to this not being a significant concern in obtaining informed consent (Murphy *et al.,* 1996; Young & Chesson, 2006).

Service users' beliefs about themselves and their sense of agency also present a barrier to their inclusion. Obtaining their views may be impeded by beliefs about lacking choice and a sense of powerlessness which renders them silenced when faced with the task of expressing their views (Gorfin & McGlaughlin, 2005). Communication difficulties also present potential challenges for researchers to overcome (Arscott *et al.,* 1998).

1.8.3 Overcoming the Barriers

Service users have shown themselves to be willing and able to participate in research given the appropriate support and much work has been undertaken to identify ways in which they may be enabled to give informed consent to take part in healthcare related research (Arscott *et al.,* 1998, 1999; Walmsley & Johnson, 2003; Young & Chesson, 2006). Preparing service users with clear explanations of what the research will involve and using accessible information tailored to the individual's specific needs can aid in overcoming this initial hurdle (Chaplin *et al.,* 2009). Enhancing service users' abilities to engage in semi-structured interviews may be achieved using augmentative communication systems to

supplement speech and pictorial support to assist in both receptive and expressive communication (Arscott *et al.,* 1998; Young & Chesson, 2006).

Including others who know the service user well to act as 'proxy researchers' to support engagement, build rapport and ensure informed consent is obtained can also contribute significantly to the achievement of service user inclusion, although this is not without its problems as outlined earlier (Nind, 2008; Walmsley & Johnson, 2003)

1.9 Service Users' Views of Community and Healthcare Services

Despite views that the inclusion of adults with a learning disability in research pertaining to community and healthcare services is still limited, the body of literature based on service users' views within this field is growing.

Service users' views and experiences have been obtained in relation to community mental health services (Hoole & Morgan, 2011; Jacques & Stranks, 2009; O'Brien & Rose, 2010), general hospital care (Gibbs *et al.,* 2008), independent community living (Bond & Hurst, 2010; Forrester-Jones *et al.,* 2002), restraint (Hawkins *et al.,* 2005) and detention under the Mental Health Act (McNally *et al.,* 2007). Furthermore, service users have shared their perceptions of support staff in forensic inpatient settings (Clarkson *et al.,* 2009) and learning disability nursing (Manthorpe *et al.,* 2003).

Applying a qualitative methodology much of this research has utilised a focus group approach as a means of opening up dialogue and exploring service users' views (Gibbs *et al.,* 2008; Hoole & Morgan, 2011; Jacques & Stranks, 2009; O'Brien & Rose, 2010). By facilitating discussion of what is of interest to participants, as opposed to answering pre-determined questions, focus groups have been shown to be effective in eliciting the views of service users (Fellows & Jones, 2011). However, whilst data from focus groups can be analysed thematically, one to one semi-structured interviews yield data which can be analysed in more depth using Grounded Theory (Hawkins *et al.,* 2005; Llewellyn & Northway, 2008) or Interpretive Phenomenological Analysis (Clarkson *et al.,* 2009; McNally *et al.,* 2007).

Given the opportunity to express their views and opinions, service users have identified a number of key issues in relation to their experiences of community and healthcare services. Themes regarding power, control, independence and inclusion feature prominently (Bond & Hurst, 2010; Jacques & Stranks, 2009; Hoole & Morgan, 2010; McNally *et al.,* 2007) as do issues of fairness, equality and respect (Gibbs *et al.,* 2008; Hoole & Morgan, 2011; McNally *et al.,* 2007). Tensions between vulnerability and support, and control and punishment are also highlighted (Bond & Hurst, 2010; McNally *et al.,* 2007; O'Brien & Rose, 2010). Research has identified that opportunities for activity and meaningful employment contribute positively to service users' experiences and that boredom and lack of activity figure negatively in their accounts (Forrester-Jones *et al.,* 2002; Rourke *et al.,* 2004). As service users often have wide networks of support around them, it is unsurprising that relationships with staff and carers provide another common theme within their narratives (Bond & Hurst, 2010; Clarkson *et al.,* 2009; Gibbs *et al.,* 2008; Rourke *et al.,* 2004).

It is clear therefore, that with appropriate support people with a learning disability are able to engage in qualitative research with the expanding body of literature exploring their views and experiences highlighting a number of key themes that dominate their accounts. As a direct consequence of these studies, service users' views have influenced the core principles underpinning services at a national level (Jacques & Stranks, 2009) and the development of local service delivery and documents (Fellows & Jones, 2011). In contrast to this growing body of literature pertaining to service users' views of community and healthcare services however, research exploring the views of adults with a learning disability regarding inpatient services remain limited.

Part 3: Service Users' and Carers' Views and Experiences of Inpatient Services: A Review of the Literature

1.10 Literature Search

In order to identify the existing literature and previous research relating to the views of adults with a learning disability on inpatient services, a comprehensive literature search was systematically carried out.

1.10.1 The Search Strategy

Three electronic databases were searched (*EMBASE, Ovid Medline (R) and PsycINFO*) for all years up until January 2012. In addition a search of the Cochrane Library was conducted and the reference lists of key articles and journals (*Journal of Applied Research in Intellectual Disabilities* and *Advances in Mental Health and Intellectual Disabilities*) were reviewed for additional published articles.

Three separate searches were carried out to obtain a comprehensive overview of the research literature. Search terms (Learning disabilit*, Intellectual disabilit*, Inpatient, In-patient, Mental Health, Psychiatric, Challenging Behaviour, Service user*, Experience*, View*) were combined using Boolean operators. Titles and abstracts generated through these searches were reviewed (N= 1,386) according to the inclusion and exclusion criteria. A summary of the literature search process is provided in appendix 1.

1.10.2 Inclusion and Exclusion Terms

To be included in this focused review of the literature, studies were required to have qualitatively examined participants' subjective views and experiences of inpatient services. An initial review of the literature highlighted a paucity of research specifically investigating service users' experiences and views in this area and it was therefore decided that research exploring carer's or staff's views and experiences would also be included if it satisfied all other criteria.

Any studies which focused on physical health experiences (e.g. dental treatment, surgical procedures), community services, forensic inpatient services or Non-UK services were excluded. Similarly, only English language studies were considered for inclusion. Research papers, theoretical articles and systematic reviews that were generated within the search and identified as relevant to the current study, but did not meet the inclusion criteria for the focused literature review, contributed to the overall write up of this research.

1.10.3 Identification of the Key Studies

In total, ten research papers were identified through the literature search which explored service users' or carers' views and experiences of inpatient services (see appendix 1).

Studies have been included in this review based on their relevance to the research topic and a critical appraisal of the full text articles using a quality standards framework based on Law *et al.* (1998) and Spencer *et al.* (2003) (see appendix 2).

The researcher concluded that three studies did not meet the inclusion criteria for this review and consequently they were not reviewed in detail, however they have contributed to the wider psychological literature that is discussed. The study by Chaplin *et al* (2006) was excluded as it focused specifically on the prevalence and experience of violence on specialist inpatient units. Furthermore, data was obtained predominantly through questionnaires with limited qualitative exploration of service users' experiences therefore it does not provide a qualitative exploration of service users' overall views and experiences. Furthermore, studies by Murphy *et al.* (1996) and Vos *et al.* (2007) explored service users' and carers' experiences of specialist and mainstream inpatient admission, respectively, but provided only descriptive findings in the form of percentages of participants who reported a given experience. Therefore, these studies were also excluded as they did not provide a qualitative understanding of participants' views and experiences. Of the seven studies remaining, two of these by Longo and Scior (2004) and Scior and Longo (2005) presented identical findings from the same study. Only the more recent of these papers was included in this review as it presented a more extended literature review, and discussion and critique of the research findings.

This review therefore focuses on six papers which are considered to have met the quality standards outlined in appendix 2, and explored service users' and carers' views and experiences of inpatient services within a qualitative methodology. Service users' views and experiences are the focus of four of the research studies (Scior & Longo, 2005: Parkes *et al.,* 2007; Donner *et al.,* 2010; Chinn *et al.,* 2011) and carers' views and experiences are the focus of four studies (Scior & Longo, 2005: Samuels *et al.,* 2007; Donner *et al.,* 2010; Bonell *et al.,* 2011). The literature review also draws upon wider psychological research and theory as well as findings from the research exploring service users' views in other related areas.

1.11 Service Users' Views

1.11.1 Summary of the Key Studies

All of the studies included in this review adopted a qualitative approach using semi-structured interviews to explore a range of aspects of service users' admissions. Scior and Longo (2005) were the first to attempt a qualitative exploration in this area using Interpretive Phenomenological Analysis to examine the experiences of 14 service users in mainstream inpatient services and 15 service users in specialist inpatient assessment and treatment units. Donner *et al.* (2010) also used Interpretive Phenomenological Analysis in their exploration of the experiences of 11 service users across five mainstream inpatient settings. Using a thematic analysis approach, Parkes *et al.* (2007) analysed data collected from 12 service users who had been admitted to a mainstream inpatient service and 19 service users who had been admitted to a newly developed integrated inpatient unit. Chinn *et al.* (2011) undertook a thematic analysis of the experiences of 17 service users across 18 out of area NHS and private specialist inpatient units. A detailed summary of the study designs, participant demographics and methodologies can be found in appendix 2.

From this body of literature the factors that might influence service users' experiences and evaluation of admission can begin to be understood. Common themes that are highlighted within the literature across inpatient settings are discussed below under the headings control and inclusion; safety, vulnerability and protection; relationships with staff; relationships with other service users; environment; the admission process; and treatment and recovery. Specific differences in experiences according to service setting are discussed in section 1.13.

1.11.2 Control and Inclusion

Research exploring service users' views of general healthcare services and the principles which they feel should underpin mental health service development, has highlighted the value that service users attribute to having choice about treatment options; the right to be treated fairly and respectfully; and control and responsibility with regards to decision making about their healthcare (Jacques & Stranks, 2009). Despite this, the current literature review on service users' experiences of inpatient services would suggest that

service users do not experience these principles and values within the inpatient services they have come into contact with.

Feelings of disempowerment were prevalent throughout the literature reviewed. Service users described threats of punishment and rigid rules which engendered feelings of disempowerment, along with beliefs that compliance with medication was synonymous with recovery. Submissiveness also characterised some service users' accounts with descriptions of them saying or doing things just to please staff (Donner *et al.*, 2010). Furthermore, research indicated that service users' tendency to be compliant, submissive and acquiescent may have the potential to result in them feeling neglected or being put at risk (Bond & Hurst, 2010; Donner *et al.*, 2010). This is supported by research within general healthcare settings where service users have identified that their reliance on staff and the power imbalance this can create resulted in significant feelings for them of unfairness, discrimination and inequality associated having a learning disability (Gibbs *et al.*, 2008; Hoole & Morgan, 2011). Therefore, whilst research has indicated that service users acknowledge their need for support from staff within mental health services, it would appear that this might be at the expense of their need and desire for control.

The studies reviewed suggested that feeling out of control was associated with service users' lack of information and uncertainty regarding key elements of treatment such as length of admission and post discharge plans (Scior & Longo, 2005). This may in part be due to failures in acknowledging the cognitive and communication needs of service users which was reported to have resulted in information not being made accessible for them and their active involvement in treatment being limited (Scior & Longo, 2005). Similar difficulties for service users in achieving a shared understanding with staff have also been expressed by service users in general hospital settings (Gibbs *et al.*, 2008). On the other hand being well informed about their care was identified as a significant contributory factor in service users feeling included, as it also was for carers (Donner *et al.*, 2010).

Donner *et al.* (2010, pp.219) reported service users' experiences of not feeling heard or listened to and having to '*fight with*' staff in order to be believed. Many service users have also described '*not having a voice*' (Scior & Longo, 2005, pp.214). Although there was evidence that feeling included was supported to some extent by service users' attendance at ward rounds, many of them experienced these as intimidating. Indeed their accounts

suggested that service users struggled to feel involved in decision making despite being present at the ward round. This suggested that attendance itself was not sufficient for inclusion or involvement (Parkes *et al.*, 2007). Within community mental health settings service users have highlighted the importance of having carers to advocate for them (Hoole & Morgan, 2011). However, within inpatient settings service users described a lack of control in managing their relationships with potential advocates such as friends and family and highlighted the need to negotiate telephone contact and visits via staff (Scior & Longo, 2005). This lack of contact with family was considered by service users to place limitations on their rights (Murphy *et al.*, 1996). Achieving a sense of control, equality, inclusion and involvement in their care may therefore be precluded for service users by difficulties in accessing and maintaining contact with carers who provide an important role as advocates.

Chinn *et al.* (2011) suggested that the limitations in choice highlighted above and the organisation of service users' schedules on a group rather than an individualised basis also contributed to a sense of de-personalisation and stand in stark contrast to the principles of choice, rights and independence. Furthermore, they proposed that lack of control, choice and inclusion within such inpatient services may be a reflection of the underlying assumption that decision making is the prerogative of staff. However, service users have identified hopes for greater control over decision making and increased inclusion in the development of community services which may support the conclusion that service users view these principles as important within inpatient settings also (Hoole & Morgan, 2011).

1.11.3 Safety, Vulnerability and Protection

Service users in the studies reviewed also described feeling vulnerable as a result of the lack of control they experienced and not knowing what was going to happen to them following admission. They commented on the benefits of staff taking time to orientate them to the ward which resulted in a reduction in feeling '*panicky*' (Parkes *et al.*, 2007, pp.26). However, other service users acknowledged that their behaviour in the community prior to admission had become worrying and out of control therefore they consequently viewed the inpatient unit as a place where they felt safer by comparison (Murphy *et al.*, 1996; Vos *et al.*, 2007).

Service users also reported that the ward environments often felt unsafe due to violence and theft of personal possessions with accounts describing service users having been assaulted and feeling at risk as a result of other patients' behaviours (Donner *et al.*, 2010; Parkes *et al.*, 2007). Scior and Longo (2005) reported that service users described a reliance on staff to keep them safe, however staff did not always meet these needs. Some reports from service users indicated experiences of staff being unfriendly, unavailable or causing actual physical harm by use of physical restraint, which exacerbated their feelings of vulnerability.

1.11.4 Relationships with Staff

Relationships with staff were recognised as being particularly important to service users as they contributed towards feelings of safety, access to activities and maintaining contact with friends and family (Scior & Longo, 2005). These relationships were characterised across service settings both positively and negatively.

Chinn *et al.* (2011) reported accounts from service users who described negative interactions with staff who were unfriendly and unsympathetic; as well as sarcastic, threatening and intimidating which service users experienced as distressing and demeaning. This is supported by evidence from local community mental health services and forensic inpatient settings where negative staff attributes such as laziness, being nasty and arrogant, and winding service users up have also been described by service users (Clarkson *et al.*, 2009; O'Brien & Rose, 2010).

High staff turnover was reported by service users to have impaired their ability to get to know staff (Donner *et al.*, 2010). Furthermore, service users often reported feeling let down, angry or frustrated as a result of staff unavailability which meant they had to wait or failed to have their needs met at all (Scior & Longo, 2005; Parkes *et al.*, 2007).

However, there were also positive accounts of relationships with staff detailed in the research reviewed and examples given by service users of staff being caring, sensitive and available to talk to (Chinn *et al.*, 2011; Parkes *et al.*, 2007). This is supported by Clarkson *et al.* (2009) who reported that service users in forensic inpatient settings found staff to

have a nurturing parental role and were positive about the familiarity and alliance with staff that they experienced.

1.11.5 Relationships with other Service Users

Relationships between service users have been found to be characterised by incidents of violence, aggression and bullying (Donner *et al.*, 2010; Scior & Longo, 2005). The unpredictability of other service users' behaviours have left service users feeling vulnerable, upset and stressed, with noise having presented a particular annoyance (Chinn *et al.*, 2011; Scior & Longo, 2005). It has been suggested that an inappropriate mix of service users may give rise to these negative experiences, particularly for vulnerable service users who were accommodated with other service users whose behaviours were violent, aggressive or sexualised (Murphy *et al.*, 1996).

In addition, service users have described difficulty in getting to know other service users, which contributed to feelings of isolation. In specialist services in particular, service users attributed this to other service users having a disability and/or limited communication skills (Scior & Longo, 2005). In contrast, relationships with other service users in mainstream settings were described more positively (Scior & Longo, 2005: Donner *et al.*, 2010) and Parkes *et al.* (2007) noted that service users in an integrated service did not report any instances of bullying or isolation. Furthermore, despite the difficulties service users reported within their relationships with other service users, positive opportunities for socialisation with other service users were also reported in all settings (Scior & Longo, 2005; Parkes *et al.*, 2007).

1.11.6 Environment

Service users' views of the physical environment in inpatient settings have been largely negative including views of the general atmosphere within the unit and frustration at the lack of privacy (Scior & Longo, 2005). Furthermore, service users also reported that being placed in facilities far away from home contributed to intense feelings of isolation from family and friends and difficulties in maintaining these significant relationships. Most service users therefore wanted more contact and to return closer to home (Chinn *et al.*, 2011). McNally *et al.* (2007) also reported that some service users detained under the

Mental Health Act experienced a sense of rejection and abandonment by their family and reported feeling lonely as a result of this separation.

1.11.7 The Admission Process

Service users also saw admission as offering themselves and their carers a period of respite, a view that was also shared by carers (Donner *et al.*, 2010). However, Chinn *et al.* (2011) reported that a number of service users viewed their admission as a form of punishment and that consequently they saw the inpatient unit as being like a prison. This perception appeared to be influenced to some extent by the fact that service users attributed the cause of their admission to their challenging behaviour and/or having been admitted via the courts following incidents of violence or aggression. Some service users in this study indicated that their negative feelings about admission were exacerbated by their perception that the admission was unfair.

Service users in inpatient settings also described difficulties in adjusting to this environment with their experiences of anxiety being linked to unfamiliarity and uncertainty (Parkes *et al.*, 2007). This is supported by narratives from adults with a learning disability experiencing general hospital care, which identified that feelings of anxiety and fear were commonly reported and were influenced by previous experiences (Gibbs *et al.*, 2008).

1.11.8 Treatment and Recovery

Chinn *et al.* (2011, pp.24) described the aims of inpatient services as providing '*a wide range of therapeutic modalities, combining psychiatric, educational, recreational and cognitive behavioural perspectives*.' Although the extent to which these aims were met is challenged by some findings (Chinn *et al.,* 2011), some therapeutic benefits of admission and treatment have been highlighted within a number of other service users' accounts.

The research reviewed suggested that activities might be considered an important aspect of service users' treatment plans with a range of activities having been identified which offer opportunities for the development of independence, choice and control in inpatient and community settings (Scior & Longo, 2005; O'Brien & Rose, 2010). Some service users reported opportunities for engagement in activities as providing both enjoyment and a

sense of purpose, although others discussed the boredom they experienced in inpatient facilities where there were few activities (Chinn *et al.,* 2011). Bond and Hurst (2010) have also highlighted the importance of activities being meaningful for adults with a learning disability who live independently within the community, concluding that positive day opportunities were linked with increased self-esteem, independence, motivation and well-being in service users. Furthermore, McNally *et al.* (2007, pp.50) described the value that service users detained under the Mental Health Act placed on having a '*role within the system such as that of 'advisor', 'carer of the other patients' or 'helper of staff.''*

The use of medication as a therapeutic intervention has received mixed views from service users. Whilst some service users viewed medication as a helpful component of their treatment plan, others experienced it as punitive when given without consent and resulted in unwanted side effects which could be embarrassing (Chinn *et al.*, 2011). Parkes *et al.* (2007) found that some service users reflected upon their knowledge of medication and reported that increased understanding of medication resulted in service users being more able to recognise its benefits. However, other service users reported apprehension about taking medication with experiences of disempowerment exacerbated by feelings that they '*had to take it*' (Parkes *et al.*, 2007, pp.27).

In addition to activity-based interventions and medical treatments, service users have discussed their experiences of psychological treatments. Service users identified the benefits they find in talking and addressing issues from the past (Chinn *et al.*, 2011). However, the availability of other psychotherapeutic treatments, for example anger management, has been identified as being limited (Chinn *et al.*, 2011; Parkes *et al.*, 2007).

Service users' views on recovery were limited within the research reviewed, however some evidence suggested that service users associated recovery largely with improvements in behaviour (Murphy *et al.*, 1996) and compliance with medication (Donner *et al.*, 2010).

1.12 Carers' Views

1.12.1 Summary of the Key Studies

The views of individuals who support and care for service users offer an additional and important insight into how we might understand the experiences of service users in inpatient settings. The research reviewed has examined the views of family and paid carers including direct support staff and community learning disability/mental health nurses. This section of the literature review builds upon the previous section by providing an exploration of the findings in relation to key themes, represented within research exploring carers' views and experiences of inpatient services.

Scior and Longo (2005) obtained the views of 10 carers in respect of mainstream inpatient services and 10 carers' views of specialist inpatient assessment and treatment units. Donner *et al.* (2010) also explored the views of nine family carers, four community nurses and seven professionals from community learning disability teams in relation to mainstream inpatient services. Both these studies used Interpretive Phenomenological Analysis. Using a thematic analysis approach, Samuels *et al.* (2007) reported the views of 12 professionals from community learning disability teams and eight family and paid carers regarding an integrated inpatient service. Bonell *et al.* (2011) also applied a thematic analysis in their examination of the views of 16 family carers across 18 out of area NHS and private specialist inpatient units. A summary of the study designs, contexts, participant demographics and methodologies is summarised in appendix 2.

1.12.2 Views on Admission

Family and paid carers have been found to be largely satisfied with both the process of admission and the positive outcomes for service users (Donner *et al.,* 2010; Samuels *et al.,* 2007). Carers have described, however, the difficult route to securing admission for service users and having to reach crisis point before services would accept the service user for admission (Donner *et al.,* 2010; Scior & Longo, 2005). In particular, carers commented on poor inter-agency working within mainstream services and a feeling of '*fighting a constant battle*' in accessing help and support which they found frustrating (Donner *et al.,* 2010, pp.220). Once admission was secured however, carers positively described the 'respite' nature of admission for themselves and for the service user. In addition, carers reported a

sense of being supported and cared for by the ward staff during the period of admission and highlighted the openness of communication between themselves and ward staff (Donner *et al.,* 2010). Furthermore, Scior and Longo (2005) reported the importance of discharge planning illustrated by carers and the impact this had on how the admission was experienced by them, particularly with regard to loss of support as a result of discharge. Findings therefore suggested that admission may serve a function not only for the service user but also for those carers who support them.

Mixed views have been expressed by carers about the length of admission (Samuels *et al.,* 2007) with Scior and Longo (2005) identifying that carers felt they would have liked a longer admission and more advice. Views on treatment varied with some carers having felt satisfied with medication and activities (Samuels *et al.,* 2007) and others having expressed concerns about service users being over medicated (Scior & Longo, 2005). On the basis of the existing research however, carers appeared to have said very little about the treatment service users received.

1.12.3 Concerns about Safety and Environment

Some carers reported that service users in mainstream services were able to mix and make friends with service users who did not have a learning disability (Scior & Longo, 2005: Samuels *et al.,* 2007). These findings would therefore suggest that mainstream services can enhance inclusion and integration of people with a learning disability. However, in line with accounts given by service users themselves, other carers have reported themselves and service users as feeling frightened of other non-learning disabled service users and described threats and instances of violence making the environment '*daunting*' (Bonell *et al.,* 2011; Donner *et al.,* 2010, pp.218). Indeed, issues of safety were raised by carers in each of the studies reviewed including concerns about theft of possessions (Bonell *et al.,* 2011; Samuels *et al.,* 2007) and locking of ward doors (Scior & Longo, 2005; Samuels *et al.,* 2007).

Carers' views of the environment reflected those expressed by service users (Scior & Longo, 2005). Mainstream ward environments were described negatively by carers as '*drab, gloomy and run-down*' (Samuels *et al.,* 2007, pp.14) and 'd*epressing, intimidating ... frightening*' (Donner *et al.,* 2010, pp.219). Specialist settings however, were described

as being '*home-like*' and were viewed more positively, perhaps highlighting the importance of the physical environment in how carers evaluated the service (Scior & Longo, 2005, pp.217). Furthermore, carers felt that mainstream environments often had a negative impact upon their relationships with service users as visits lacked privacy (Donner *et al.,* 2010). This would suggest that maintenance of significant relationships within the service user's life may be affected by admission.

1.12.4 Relationships with Ward Staff

The nature of carers' relationships with staff was a recurring theme throughout the research reviewed. Carers described difficulties in communication with staff, limited contact, frequent use of agency staff, and lack of continuity as barriers to ensuring effective care planning (Scior & Longo, 2005; Samuels *et al.,* 2007). The lack of continuity and consequential difficulty in knowing who to liaise with led to some carers finding it difficult to establish trusting relationships with staff which they experienced as disorientating and upsetting (Scior & Longo, 2005).

1.12.5 Relationships with Service Users and Involvement in Care

The role of carers and their ongoing involvement in service users' care stood out as another key theme within the literature reviewed. Attendance at ward rounds was described as providing an important opportunity for carers to be involved in service users' care (Samuels *et al.,* 2007) and carers acknowledged the positive role they played as advocates during these meetings (Bonell *et al.,* 2011). Carers held a strong sense that staff in mainstream and integrated settings failed to appreciate service users' cognitive and communication needs (Donner *et al.*, 2010). With service users therefore feeling disempowered and unable to make their needs or wishes known, carers viewed their role as advocate as an important one. However, with carers having reported feeling left out, ignored, devalued and lacking in information, it is likely that the experience of disempowerment for both carers and service users was perpetuated and service users' voices lost within the complex inpatient system (Bonell *et al.,* 2011; Donner *et al.,* 2010; Scior & Longo, 2005). Where a more collaborative relationship was reported to exist between carers and ward staff, carers viewed the admission more positively and were more accepting of its negative aspects such as the use of restraint (Scior & Longo, 2005).

In relation to experiences regarding out of area placements, Bonell *et al.* (2011) found that some carers felt as if their relationships with service users had been damaged for good and expressed beliefs that service users would never be able to return to their care. Carers described how the distance between themselves and service users meant contact and advocacy was difficult to maintain which exacerbated carers' feelings of upset. In contrast, some carers judged this distance as contributing positively towards service users being away from bad influences in the local area and feeling settled on the unit (Bonell *et al.,* 2011). On the whole however, distance was found to be a barrier to carer involvement and caused strain within carer-service user relationships with consequential social exclusion and loss of community links on the part of the service user (Bonell *et al.*, 2011).

1.13 Differences in Views Across Services

The themes explored above were prevalent throughout the research conducted in specialist, mainstream and integrated services with mixed positive and negative views expressed. However, Scior and Longo (2005) provided the opportunity for direct comparison of carers' and service users' views between mainstream and specialist inpatient services, as summarised below.

In particular, differences were noted in services users' experiences of relationships with other service users. Scior and Longo (2005) found that greater feelings of isolation with less positive evaluation of relationships between service users were reported in relation to specialist services. In contrast, service users in mainstream settings identified that services promoted positive relationships and consequently greater integration and normalisation was achieved within these settings. Service users in mainstream inpatient units, however, were also more likely to feel vulnerable, disempowered and lacking in freedom than those in specialist settings.

Views on staff's attitudes also evoked different reports from service users and carers across settings. Whilst in specialist services staff were described as caring and involving of carers who reported higher levels of information sharing, in mainstream services experiences of staff's attitudes and behaviour were less favourably described. Accordingly, carers viewed staff in mainstream settings as '*at best…under-involved, at worst rejecting of the service user*' (Scior & Longo, 2005, pp.216). Service users and carers also reported feeling less

supported, more stressed and less trusting in mainstream settings. Carers were more optimistic about discharge arrangements from specialist services with admission largely being viewed more positively as having provided respite. In conclusion Scior and Longo (2005) proposed that specialist environments were generally evaluated more favourably particularly with regards to service users' experiences.

1.14 Summary of Literature Review and Relevant Theory

The research reviewed, from both service users' and carers' perspectives, highlighted a number of factors which appear to have influenced service users' views and experiences of inpatient admission. However, previous studies have focused upon providing thematic or phenomenological accounts of service users' experiences and in doing so have given little consideration to psychological theory in order to make sense of these. Whilst the importance of relationships with staff and carers are highlighted in the literature, for example, these are not explored from theoretical perspectives which might contribute to a more psychological understanding of how these factors influence service users' experiences. This may reflect the limited application of social constructionist, systemic and attachment theories overall with regards to understanding service users' experiences, perspectives and relationships within the field of learning disabilities and challenging behaviour. It is therefore proposed that the factors contributing to service users' experiences identified in the existing literature may be understood by drawing upon social constructionist, systemic and attachment ideas, as discussed below. Accordingly, these approaches may be considered useful in making sense of the results obtained within the current study.

1.14.1 The Creation of Meaning

The research reviewed indicated that service users' understanding of different aspects of their admission and the meaning that they attributed to them appeared to influence how they were experienced (Donner *et al.,* 2010; Scior & Longo, 2005; Parkes *et al.,* 2007). The meaning service users made of their admission seemed to be influenced by a range of factors including their relationships and interactions with other service users, staff and family; and repeated experiences such as being assaulted or lacking information. Social constructionist approaches propose that meaning, experience and identity are constructed,

and may therefore be understood, within the context of such relationships, interactions and patterns of behaviour (Freedman, 2001; Pearce, 2004).

1.14.2 The Relational Context

The application of systemic theory to understanding the experiences of service users is supported by findings that people with a learning disability often experience multiple networks of support including family, social care services, residential support and healthcare professionals (Lynggaard *et al.,* 2001; Baum, 2006, 2007). The literature reviewed indicated that service users in inpatient settings were members of multiple systems, describing relationships with other service users, staff, family members and community mental health services (Donner *et al.,* 2010; Scior & Longo, 2005).

In line with social constructionist thinking, systemic approaches propose that individuals are connected in relationships with one another and that experiences are constructed and understood in relation to reciprocal patterns of interactions and behaviours occurring within a given context (Baum, 2006; Freedman, 2001; Vetere & Dallos, 2003). In accordance with this thinking, the research reviewed indicated that the context of the service setting and differences in how service users related to staff and other service users were linked to differences in their experiences of admission (Scior & Longo, 2005). Service users' feelings of safety in inpatient settings were also thought to be influenced by their relationships with other service users (Bonell *et al.,* 2011; Donner *et al.,* 2010) as were feelings of isolation (Scior & Longo, 2005). The effects of service users' relationships with staff on their experiences of control, inclusion and being heard were also indicated in the research reviewed (Chinn *et al.,* 2011; Donner *et al.,* 2010; Scior & Longo, 2005). Service users' experiences of being involved in their care were also linked to maintaining family contact and having carers who adopted an advocacy role (Bonell *et al.,* 2011; Scior & Longo, 2005).

Attachment theory (Bowlby, 1969, 1973, 1980) also emphasises the influence of relational factors upon experiences, in particular experiences of separation, loss and safety. Bowlby (1969) proposed that in response to threat or distress individuals seek out attachment figures. This model may therefore provide a useful framework for understanding service users' and carers' responses to being separated as a result of admission, their desire to

maintain contact and the impact of distance upon service users' experiences (Chinn *et al.* 2011).

The nature of relationships between service users and inpatient unit staff may also be considered within an attachment perspective. Lynggaard (2005) suggests that as some adults with a learning disability have significant dependences on support staff to meet their physical, social and emotional needs, these relationships may particularly important. It may therefore be considered that these could be conceptualised as attachment relationships for service users.

1.15 Study Limitations

Limitations of each of the studies detailed in this review are summarised in appendix 2 with specific issues identified in relation to methodological limitations, generalisability of findings, limited description of service settings and sampling bias.

Of the six key studies discussed within this review only two provided an interpretive analysis of the data using Interpretive Phenomenological Analysis (IPA) (Donner *et al.*, 2010; Scior & Longo, 2005) with the remaining four providing a thematic exploration of the data (Bonell *et al.*, 2011; Chinn *et al.*, 2011; Parkes *et al.*, 2007; Samuels *et al.*, 2007). However, critical appraisal revealed that only four papers provided a suitably thorough and transparent description of the process of analysis and inclusion of strategies to ensure credibility checking (see appendix 2). Furthermore, whilst the key studies offered a thematic understanding or interpretation of service users' and carers' views and experiences, there have been no attempts to synthesise this into a theoretical model or framework for understanding this phenomenon.

An inherent difficulty in undertaking qualitative research with people with a learning disability is the ethical and methodological necessity for participants to have a level of cognitive and communication ability to provide informed consent and engage in the research process. Consequently the findings discussed reflected predominantly the views of service users with a mild learning disability and the issues and themes identified in studies may be specific to this population. This is of particular relevance in understanding the differences between service users' experiences in mainstream and specialist services

where the wider service user population is likely to have a greater or lesser degree of learning disability than the participating service user. In addition to this, interviews in a number of the studies were conducted with service users up to three years post discharge, thus introducing the potential for limited recall associated with duration of time elapsed since admission (Donner *et al.,* 2010; Parkes *et al.,* 2007).

A further methodological limitation arises from the sampling bias which occurs as a consequence of service providers managing the recruitment process. Whilst it is recognised that it would be unethical for researchers to make the initial approach to service users, Chinn *et al.* (2011) and Donner *et al.* (2010) pointed out that the views of service users considered not to be appropriate participants by service managers were excluded, and the views presented were therefore potentially biased. In addition, the views expressed by service users in Donner *et al.* (2010) were likely to have been influenced to some degree by the presence of support staff during interviews.

This review of the literature identified that carers offer a useful perspective that can contribute meaningfully towards understanding service users' experiences. Indeed Walmsley and Johnson (2003) advised that only including service users in research may "*exclude groups from contributing to a richer more extensive view of the issues affecting the lives of people with a learning disability*" (pp.143). Furthermore, Jackson (2000; pp.xiii (cited in Walmsley & Johnson, 2003)) writes that "*at one level research should involve the process of uncovering, listening to and learning from the experiences of people with a learning disability. And yet, if we are to comprehend those experiences fully, we need to cast our net wide*". However, it is important that carers are able to provide a reliable account of the service user's experience if it is to contribute to our understanding of this. The extent to which carers in the research reviewed were involved with services and service users during periods of admission and were therefore able to comment on the service users' experience was unclear (Bonell *et al.*, 2011; Samuels *et al.*, 2007). Furthermore, exploration of multiple perspectives was limited with no inclusion of ward staff who worked with service users during admission on a daily basis.

The findings discussed in this review provide a useful starting point from which to begin to understand the experiences of adults with a learning disability in inpatient settings. However, although research has examined all three service models and attempted to

provide some insight into the differences in service users' and carers' experiences across settings, there remains a paucity of literature. In particular the experiences of service users within any one service model are still limited in their exploration. Furthermore, two of the studies focused on out of area inpatient services (Chinn *et al.*, 2011; Bonell *et al.*, 2011). Whilst the experiences of service users in these settings appeared to share some similarities with those in other settings, the possibility that the experiences of adults with a learning disability in specialist services in their locality areas would be different cannot be excluded. Chinn *et al.* (2011) therefore recognised the need to explore the experiences of service users in specialist units in their locality area. To date no research studies have undertaken a specific investigation of this area.

Part 4: Rationale, Aims and Objectives

1.16 Rationale, Aims and Objectives of Current Study

1.16.1 Rationale

The current study was influenced by Government policy which advocates that the views of service users and other stakeholders need to be heard in order that direct clinical practice and service development can be informed and driven by the experiences of those accessing the services. This research therefore contributes towards the larger body of literature pertaining to service users' views of healthcare in accordance with Government priorities and research aims within this field. More specifically, this study has been undertaken in order to build upon the existing body of literature relating to service users' views of inpatient services as discussed above and in response to a number of key limitations highlighted by a review of the literature.

The literature reviewed identified that despite a Government drive for the use of mainstream inpatient provision for adults with a learning disability, there is recognition that the needs of some service users may be best met in specialist services (Royal College of Psychiatrists, 2003). Furthermore, findings point towards the experiences of service users in mainstream and specialist facilities varying greatly, particularly with regards to factors such as relationships between service users, feelings of safety and control, and

relationships with staff. The negative experiences of vulnerability and disempowerment expressed by service users within mainstream services challenge the Government push for the use of this model. The researcher therefore proposes that understanding the views and experiences of service users in each of these settings is vital in order to inform service development, local policy and ensure individuals' needs can be matched to the most appropriate service model. To date, no study has focused explicitly on exploring the views of service users within local specialist services despite the fact that this model of service provision is still widely used. It is therefore important that the experiences of this specific population are considered.

Previous research has obtained service users' views post discharge and consequently introduced possible recall difficulties. Therefore in order to avoid issues of delayed recall the researcher interviewed service users during their admission period. Furthermore, a novel research methodology was utilised in comparison to those used within the existing literature. In order to enhance the richness of the information obtained, multiple perspectives on the service users' experience were explored (Walmsley & Johnson, 2003). This approach is in line with systemic thinking which proposes that behaviours and experiences may be understood from multiple perspectives which generate more or less helpful ways of understanding patterns of relating in a system rather than ideas which are considered either truthful or wrong (Vetere & Dallos, 2003). Only carers and staff who had maintained contact with the service user during their admission and therefore knew them well enough to comment on their experience were included to avoid limitations acknowledged in previous studies (Bonell *et al.*, 2011; Samuels *et al.*, 2007).

Although the literature described in this review provides a meaningful understanding of service users' views and experiences, no studies have attempted to synthesise this data into a theoretical explanation of service users' experiences. The present study therefore employed a Grounded Theory approach to construct meaning around how individuals understand and make sense of events. Using this methodology service users', carers' and staff's views were explored and analysed in order to develop a theoretical model which will directly inform clinical practice and the development of specialist inpatient services for adults with a learning disability.

1.16.2 Aims and Objectives

The current study aimed to build on the existing literature by exploring service users' experiences of specialist inpatient assessment and treatment units from multiple perspectives. Furthermore, using a Grounded Theory methodology this study aimed to integrate the views of service users, carers and staff in order to develop a theoretical model by which service users' experiences can be understood. In doing this, a number of limitations and gaps within the existing literature around service users' experiences of inpatient admission are addressed.

Specifically the study had three main aims:

1. To elicit service users' experiences of their admission in local specialist assessment and treatment units.

2. To elicit the perspectives of carers and staff on service users' experiences of admission.

3. To integrate the views of service users, carers and staff into a theoretical model for understanding the factors that contribute to service users' experiences of inpatient admission.

Using semi-structured interviews the researcher aimed to elicit views on of a broad range of elements related to service users' experiences based upon previous research findings. The researcher also aimed to generate findings which would directly inform clinical practice and staff training within specialist inpatient settings as well as contribute towards policy and service development regarding the wider provision of mental health services for adults with a learning disability.

CHAPTER 2: METHODOLOGY

2.1 Chapter Overview

The aim of this study was to explore the experiences of adults with a learning disability in specialist inpatient assessment and treatment units from the perspectives of service users, carers and staff. A further aim of the study was to integrate these multiple perspectives into a theoretical model for understanding the factors that contribute to service users' experiences.

This chapter provides an overview of the qualitative research methodology employed to meet these aims, namely Grounded Theory (Glaser & Strauss, 1967), outlining its philosophy, the rationale for its use and the Grounded Theory process. The guidelines adhered to in order to ensure the quality of the research are then highlighted (Elliott *et al.,* 1999) and a summary of the participants and research procedures is presented.

2.2 Design

A qualitative methodology, guided by the principles of Grounded Theory (Glaser & Strauss, 1967), was used to develop an understanding of the experiences of adults with a learning disability in specialist inpatient assessment and treatment units. Three service users participated, each of whom nominated a carer and a staff member who also took part. Semi-structured interviews were therefore conducted with nine participants in total.

2.3 Qualitative Methodology

2.3.1 Overview of Qualitative Methodology and Philosophy

Qualitative research methodologies are concerned with gathering information about how people experience particular events or phenomenon in order to construct meaning around how they understand and make sense of the world (Willig, 2008). Qualitative methodologies are therefore interpretive and in contrast to quantitative approaches, their objective is to '*describe and possibly explain events and experiences, but never to predict*' (Willig, 2008, pp.9). Such methodologies are becoming increasingly popular in a range of disciplines where quantitative research was previously favoured.

2.3.2 Rationale for using Qualitative Methodology

A qualitative research methodology was adopted in the current study as it enabled the researcher to address existing gaps in the literature and fulfil the research aims by exploring the complex details and variability in service users' experiences of specialist inpatient admission. The essence of this experience and how it might be understood would be difficult to obtain using traditional quantitative methodologies which are designed to measure variables, test theories and analyse results using statistical methods. Furthermore, as the current study aimed to develop a theoretical model for understanding the factors that contribute to service users' experiences a qualitative methodology was well suited.

2.4 Grounded Theory

2.4.1 Overview of Grounded Theory Philosophy

In recent years the acceptability of qualitative approaches to research and their contribution to the literature alongside quantitative approaches has been increasingly acknowledged (Pope & Mays, 2006). Numerous qualitative research methodologies are now widely applied in psychological research including Discourse Analysis, Interpretive Phenomenological Analysis and Grounded Theory (Willig, 2008).

Grounded Theory was developed by sociologists Glaser and Strauss (1967) who argued that quantitative approaches failed to facilitate the 'emergence' of new ways of understanding experiences as they aimed only to test hypotheses driven by existing theories. Grounded Theory is an inductive approach, therefore the researcher does not begin with a hypothesis which they aim to confirm or disconfirm. Rather, the researcher has a set of aims and questions designed to explore individuals' accounts of their experiences and social worlds in order to identify concepts and relationships within these accounts. Through a process of systematic analysis these are then organised into a theoretical explanatory system which makes sense of individuals' experiences and is 'grounded' in the data. Grounded Theory is therefore both a product generated from the data, as well as a systematic process of sampling, data collection and analysis (Charmaz, 2006).

Grounded Theory has undergone a number of changes and revisions in response to criticisms of Glaser and Strauss' (1967) original development of the approach. In particular, there has been considerable debate as to whether Grounded Theory can be conducted with no prior assumptions or biases as initially postulated. Furthermore, the extent to which the researcher should engage with the existing literature before data collection and analysis is questioned (Charmaz, 2006). Corbin and Strauss (2008) have proposed that some degree of researcher bias or theoretical sensitivity is inevitable and may even be considered beneficial in attuning the researcher to important concepts within the data. In response to these claims by Corbin and Strauss (2008) the researcher conducted a brief review of the literature in the development stage of this study in order to highlight important areas of focus for the data collection and to increase their awareness of issues of particular relevance during the data analysis process.

The underlying philosophy that theories 'emerge' from the data independent of the role of the researcher has also received criticism. It has been suggested that this epistemological position does not fit with the constructivist origins of other qualitative approaches, which view knowledge as being created within the context of cultural, societal and historical relationships (Willig, 2008). Accordingly, Charmaz (2006) has proposed that grounded theories are not 'discovered' but are 'constructed' within the context of the researcher's experiences, perspectives and relationships to the data and analysis. Therefore, Grounded Theory is viewed as offering '*an interpretive portrayal of the studied world, not an exact picture of it*' (Charmaz, 2006, pp.10). In accordance with this epistemological position, Pidgeon and Henwood (1996) recommend careful documentation of research processes at every stage to highlight the researcher's relationship with the data and involvement in the analysis process, thereby increasing reflexivity and transparency regarding the researcher's influence on theory construction (see section 2.6.1).

2.4.2 Rationale for using Grounded Theory

It has been suggested that Grounded Theory is an appropriate methodology to employ when little is known about a phenomenon (Corbin & Strauss, 2008). Based on the research reviewed it is evident that there is little theoretical understanding of how service users experience and make sense of admission on specialist inpatient units. The researcher was also interested in exploring change processes or transitions that service users might have

experienced whilst on the unit and Grounded Theory is again considered to be useful in exploring these phenomenon (Strauss & Corbin, 1998).

The aim of this research was to explore service users' experiences by drawing upon and integrating multiple perspectives into a single theoretical understanding. Previous research has used Interpretive Phenomenological Analysis to explore service users', carers' and staff's experiences individually, however Grounded Theory provided a methodological approach which enabled all three perspectives to be drawn together into one theoretical understanding. It is argued that by drawing upon multiple informant perspectives the current study was able to obtain a richer understanding of the complexity of service users' experiences of admission on specialist assessment and treatment units than might otherwise have been achieved (Walmsley & Johnson, 2003).

2.5 The Grounded Theory Process

The process of Grounded Theory involves a number of key principles and practices (Charmaz, 2006). These include data collection, categorisation and conceptualisation. As patterns and relationships are identified between categories and concepts, a theoretical understanding of how concepts relate to each other and make sense of the whole is constructed. However, these stages are not discrete but rather iterative or repeating processes which occur flexibly alongside one another (see figure 2.1). Engaging in data collection, analysis, reflection and theory generation simultaneously enables the researcher to ground the theory in the data (Willig, 2008).

Figure 2.1: Diagrammatic Representation of the Grounded Theory Process
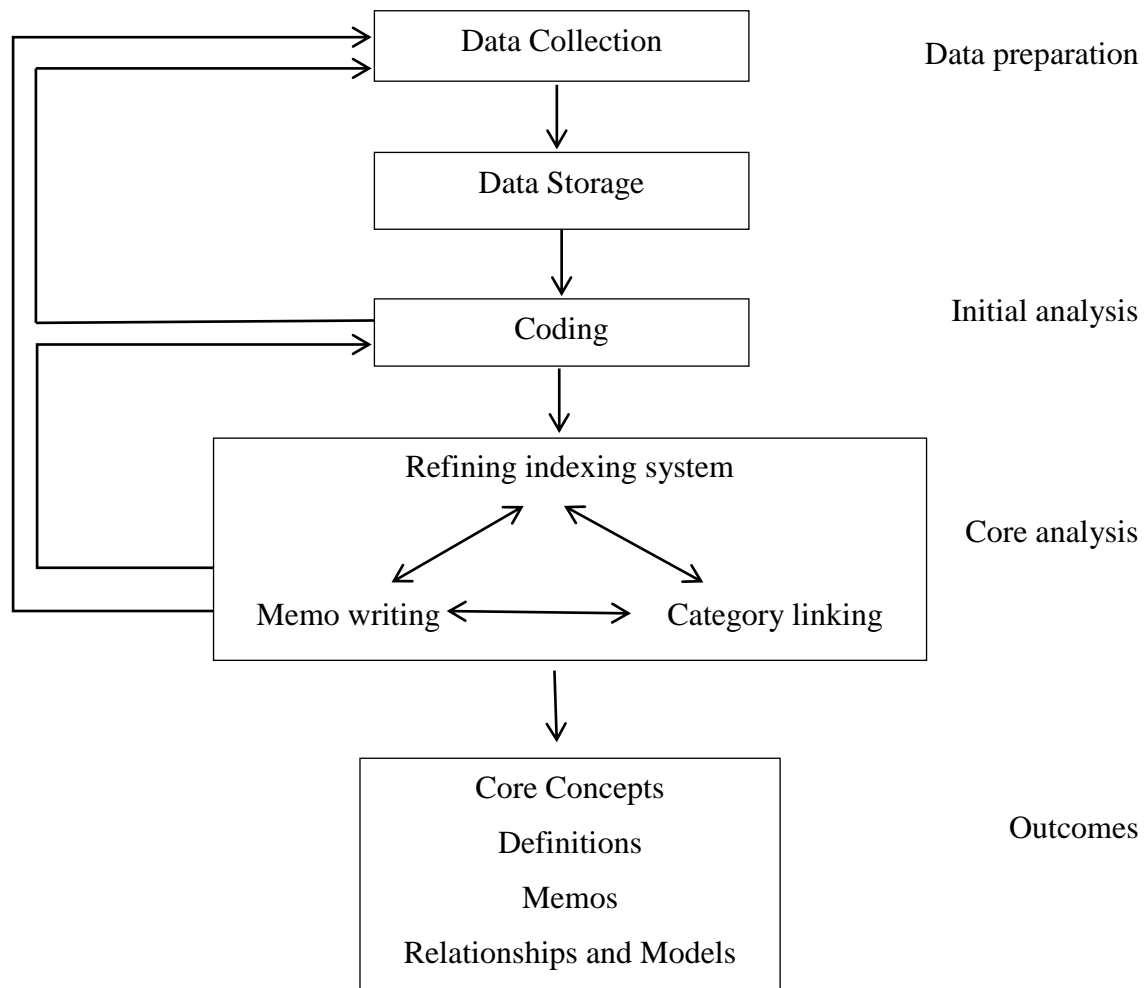
Reproduced from Pidgeon and Henwood (1996, pp.88)

2.5.1 Data Collection

Grounded Theory can be conducted using '*almost any form of qualitative material*' (Pidgeon, 1996, pp.77). Data can be collected using a number of techniques, including obtaining data directly from the source or gathering it indirectly from existing texts or documents. Commonly, data is collected by means of audio-recorded or video-taped face to face interviews which are then transcribed to retain the detail of the data and to minimise data reduction prior to analysis (Willig, 2008).

In order to guide individuals in giving a focused account of their experience, whilst allowing them the flexibility to freely and openly offer information about it, the use of semi-structured interview schedules is recommended (Willig, 2008). This facilitates a breadth and depth in the data collected which is not constrained by pre-existing categories.

As data collection and analysis progresses, interview schedules may be altered to reflect the emerging themes and more focused interview questions used.

2.5.2 Open Coding and Categorisation

Early stages of analysis involve the researcher repeatedly reading and asking questions of the data within a process of 'open coding' (Strauss & Corbin, 1998). Meaningful units, which may be words, phrases, sentences or longer segments of text, are highlighted and labelled. These descriptive labels are referred to as 'categories' (Willig, 2008). This process of open coding thus allows the researcher to capture the detail, variation and complexity of the data (Strauss & Corbin, 1998).

2.5.3 Constant Comparison

As more data is coded and categorised, constant comparisons are made to explore similarities and differences with existing categories. New categories or subcategories may therefore be identified. Previously coded transcripts are revisited with these new categories in mind and recoded as appropriate. Throughout this process of shifting between data and categories, multiple interpretations of the data are considered.

2.5.4 Theoretical Sampling

Data collection and analysis occur alongside each other with key themes, ideas and interesting patterns within the data being used to guide subsequent data collection. As analysis progresses interviews are shaped according to preliminary findings and theoretical sampling occurs as consideration is given to the recruitment of participants who will add meaningful data to test the developing hypotheses and theory.

2.5.5 Axial Coding and Theoretical Saturation

Axial coding describes the process of relating categories and concepts to one another. Previously identified categories and concepts may be relabelled, merged or split to take account of new interpretations, links, relationships and patterns. Axial coding and theoretical sampling occur alongside one another until 'theoretical saturation' is achieved, meaning no new categories are identified and additional data simply confirms what is

already known (Strauss & Corbin, 1998). However, it is recognised that the continuous process of axial coding may preclude the arrival at a final point of saturation as the researcher is constantly alert to alternative perspectives. The developing 'theory' is therefore not the end of the Grounded Theory process but rather a point at which a suitable understanding of the data has been obtained which is useful (Glaser & Strauss, 1967).

2.5.6 Memo Writing

Memos provide a written record of the process of theory generation; documenting definitions of categories, justification of labels chosen, the nature of relationships between categories and concepts, and reflections on the research. Consequently, memos offer the researcher a means to '*externalise the analysis and the process of interpretation*' (Pidgeon, 1996, pp.85). They are a useful tool in understanding and following the analytic process, as well as for stimulating theorising (Pidgeon & Henwood, 1996). Appendix 3 presents extracts from the researcher's memos.

2.6 Ensuring Quality in Research

The interpretive nature of qualitative research methodologies has led to claims that they lack credibility and are unsystematic (Pope & Mays, 2006). The applicability of 'reliability' and 'validity' as ways of evaluating their quality has also been questioned and the use of small samples has been criticised on the basis that they are unrepresentative and so findings cannot be generalised to the wider population (Golafshani, 2003).

In response to these claims Elliott *et al.* (1999) propose a set of guidelines for ensuring the legitimacy, credibility and quality of qualitative research. The researcher applied these quality guidelines to the current study to ensure and evaluate its methodological quality. A summary of the guidelines and their application to the current research is presented below.

2.6.1 Consideration of the Researcher's Position

Researchers are encouraged to adopt a position of reflexivity and '*owning one's perspective*' (Elliott *et al.,* 1999, pp.221).

> *'Reflexivity requires an awareness of the researcher's contribution to the construction of meaning throughout the research process, and an acknowledgement of the impossibility of remaining outside of one's research matter while conducting research'* (Willig, 2008, pp.10).

Researchers are urged to '*explore the ways in which [their] involvement with a particular study influences, acts upon and informs such research*' (Willig, 2008, pp.10). It is therefore recommended that researchers explicitly state their relationship to the research topic and remain vigilant to the potential contribution of their own values, assumptions and interests in the area to data collection, analysis and interpretation (Elliott, *et al,* 1999). This serves to increase the transparency and credibility of the research and assists researchers in maintaining an open minded and critical approach (Pope & Mays, 2006).

In the current study the researcher's background, orientation, beliefs, assumptions and relationship to the research topic are summarised in section 2.10. Reflexivity was also ensured by maintaining a reflective diary which tracked the researcher's assumptions, thoughts and feelings throughout the research process (see appendix 4).

2.6.2 Situating the Sample

A description of the participants serves to enable the researcher to evaluate the generalisability of the findings to the population considered.

A summary of the participants in the current study is presented in order to provide the reader with sufficient information to understand the nature and context of the findings (see section 2.8.4).

2.6.3 Grounding in Examples

An overriding principle of Grounded Theory is that the theory is 'grounded in the data'. Consequently, examples of the data should be provided in order to highlight the process of analysis and exemplify the 'fit' between the data and the sense that is made of it by the researcher. This transparency allows the reader to consider whether the proposed theory is grounded in a credible interpretation of the data.

An example of data coding and categorisation is provided in appendix 5 which shows an extract from a coded transcript. Furthermore, quotes from the data are presented throughout Chapter 3 to describe the categories and concepts generated and to illustrate the analytic process and understanding developed.

2.6.4 Credibility Checks

It is suggested that the credibility of categories and concepts is verified with another individual who has an understanding of the research area and/or the method of analysis employed. Participants may also be involved in this process of credibility checking.

The researcher ensured a process of credibility checking was achieved in the current study by discussing emergent categories and concepts with both the academic and clinical supervisors. Themes were also presented to Clinical Psychologists working in this field for discussion and their views were taken into account when constructing the Grounded Theory. Unfortunately, it was not possible to verify themes with participants due to time constraints.

Elliot *et al.* (1999) described the principle of triangulation as a means of credibility checking. This strategy involves the collection of data from multiple sources, or the use of quantitative data, for the purpose of validating the themes generated (McLeod, 1994; Golafshani, 2003). This approach however, has little meaning within the social constructionist model of Grounded Theory used in this study in which each perspective was considered to add something meaningful to the theory constructed. The purpose of obtaining multiple perspectives in this study was therefore not '*aimed merely at validation but at deepening and widening one's understanding*' (Olsen, 2004, pp.1).

2.6.5 Coherence

The data, analysis and findings should be presented in a logical and intelligible way, whilst retaining the nuances in the data, to provide a comprehensive account.

Both written and diagrammatic representations of the data are provided in Chapter 3 and were discussed with the researcher's academic and clinical supervisors in order to maximise coherence.

2.6.6 General vs Specific Research Tasks

Research should be undertaken and presented with clear aims which specify whether an understanding of a general or a specific phenomenon is sought. Where the aim of research is to generate a general understanding this should be based on an appropriate range of participants. Where a specific understanding is sought, specific instances should be described systematically and comprehensively (Pidgeon & Henwood, 1996).

The aims of the current study are presented in Chapter 1 and a summary of the participants provided in section 2.8.4. The findings are presented in a way which clearly displays the outcomes of the analysis (see Chapter 3) and limitations to the generalizability of the findings are discussed in Chapter 4.

2.6.7 Resonating with the Readers

The research and its findings should be presented in a way which accurately reflects the subject matter for readers and clarifies or enhances their insight into it in a useful way.

The researcher aimed to present the material in the current study in a way that represented the experiences of participants. Draft versions of each Chapter were read by the researcher's clinical and academic supervisors and feedback provided in order to ensure this aim was met and to enhance resonance with the readers.

2.7 Ethical Considerations

2.7.1 Obtaining Ethical Approval

A research proposal was submitted to the local Research and Development Department (R&D) where the researcher was employed. R&D approval was granted in May 2011 (see appendix 6). Ethical approval was obtained from the South East Wales Research Ethics Committee Panel D in June 2011 (see appendix 7). Written permission to undertake the

research was also gained from the R&D department of the host health board in which the research was undertaken (see appendix 8) and verbal permission was obtained from the lead manager of the services in which participants were recruited.

2.7.2 Obtaining Informed Consent

The researcher adhered to guidance for obtaining informed consent from the British Psychological Society (BPS, 2009, 2011). Guidelines for conducting qualitative research with people with learning, communication and other disabilities were also followed (Nind, 2008). In order to enhance comprehension and ensure informed consent was obtained, all written information for service users was supported visually following guidance on how to make information accessible for people with a learning disability (CHANGE, n.d), and was presented to service users by familiar inpatient unit staff. Different procedures were in place for recruiting service users, carers and staff therefore separate information sheets and consent forms were provided (see appendices 9, 10, 11 & 12).

All potential participants were provided with an information sheet by the assessment and treatment unit manager, or member of staff in charge, during the recruitment phase of the study (see appendices 9 & 10). The information sheet explained the exact nature of the study and what participation would involve as well as outlining the potential costs and benefits of taking part. Participants were informed that they were under no obligation to participate and could withdraw their consent at any time. Service users were informed that participation in the study would not affect their treatment or discharge. Issues of confidentiality, data collection, storage and analysis were also highlighted.

Participants were asked to return a consent form to the researcher declaring their informed consent to take part and giving their contact details (see appendices 11 & 12). The consent forms included confirmation that participants:

- had read and understood the relevant information sheet
- had asked any questions they had regarding the research
- understood participation was voluntary and could be withdrawn at any time
- understood how confidentiality would be maintained
- agreed for data from their taped interview to be included in the final report

- consented to take part in the research
- consented for the researcher to interview a carer and a specified member of staff from their key work team (service user consent forms only)

Prior to and following interview the researcher reviewed the consent form with the participant and verbal consent was re-affirmed. In order to ensure *informed* consent was given by service users, the information sheets were re-presented by the researcher and clarification sought that service users fully understood what they were consenting to.

2.7.3 Maintaining Confidentiality

Procedures were in place to ensure the confidentiality of all participants during the research process. The researcher was bound by the British Psychological Society Code of Human Research Ethics (BPS, 2011), the British Psychological Society Code of Ethics and Conduct (BPS, 2009) and the Data Protection Act (1998).

Every effort was made to ensure confidentiality, however participants were made aware of the limits of confidentiality through the information provided. They were informed that the researcher would share with the assessment and treatment unit manager, or lead manager, any information disclosed as necessary in order to ensure the welfare of participants or others. Confidentiality was ensured using the process detailed below.

During the recruitment phase the manager of the assessment and treatment unit, or a member of staff in charge, made initial contact with potential participants. Their details were only made known to the researcher when they returned the consent form. Participants were allocated a pseudonym which was used to code their transcripts and personal information, and these were stored separately. Only the researcher had access to this information and knew which participant each pseudonym was linked to. Any identifiable information such as places, names of other service users or staff members was anonymised or excluded from the transcripts. Transcripts were analysed solely by the researcher, with only anonymised excerpts shared for the purposes of credibility checking (see section 2.6.4).

2.7.4 Ensuring the Welfare of Participants

It was not anticipated that there would be any adverse effects for participants as a result of taking part in this study other than the time commitment which participants were informed of at the time of giving their consent. However, the researcher was aware of the possibility that themes may arise during the interviews which could be of a sensitive nature, therefore a protocol was developed to risk manage any potential distress which occurred.

Prior to commencing the interviews, the researcher re-affirmed with service users that they were happy to take part and the option for a member of staff to accompany them was offered. All three service users requested a member of staff remain present, which was facilitated. During the interview the researcher remained vigilant for any changes in the service user's mood or indications that a break in the interview may be necessary. No incidents of challenging behaviour occurred.

Participants were informed that the research interview could be stopped or postponed if they became distressed or did not wish to continue for any reason. Appropriate avenues of support for participants were in place: these included the researcher offering emotional support, the opportunity to speak to another member of staff or referral to someone independent of the research to discuss the issues raised in more depth. None of the participants required this additional support.

Risk assessments were also carried out to ensure the researcher's safety during service users' interviews. Unit staff were consulted about the possibility of challenging behaviour occurring and risk management strategies currently in place were adhered to by the researcher.

2.8 Participants

2.8.1 Inclusion Criteria

The following inclusion criteria were applied:

(i) Service users:

- Over the age of 18

- Currently a compulsory or voluntary inpatient in an assessment and treatment unit.

- Possessed a level of cognitive ability and verbal communication which enabled them to provide informed consent and participate in the research process.

(ii) Carers:

- Over the age of 18

- Family members or paid carers

- Involved in supporting the service user for at least 6 months prior to admission and maintained regular contact during the admission

- Nominated by service user who consented to them taking part

(iii) Staff members:

- Over the age of 18

- Qualified or unqualified member of the service user's key work team

- Supported the service user throughout their period of admission

- Nominated by service user who consented to them taking part

2.8.2 Exclusion Criteria

The following exclusion criteria were applied:

- Staff members who had taken a significant period of leave during the service user's admission were excluded as it was felt they would not be able to comment on all aspects of the service user's experience.

- Staff members or carers who accompanied the service user during their interview were excluded as their knowledge of the service user's account might have biased the perspective they provided.

2.8.3 Recruitment of Participants

Participants were recruited across three specialist inpatient assessment and treatment units from within one Health Board in South Wales. The units were geographically separate and had individual management and staff teams, however the structure and philosophy of the units were consistent with one another, with a lead manager overseeing their operational running. There were a total of 24 beds across the three units. Service documentation described the aim and role of these specialist inpatient units as being *"to provide a locally delivered comprehensive specialist health service for people with a learning disability [by] offer[ing] short-term in-patient assessment and intervention facilities for adults with learning disabilities whose behaviours present exceptional challenges, or who have mental health problems which pose complex behavioural and or mental health issues."* All of the units applied a positive behavioural support (PBS) approach to the assessment and treatment of challenging behaviour. The core philosophy of this values-led model is to maintain the dignity of people with a learning disability and minimise or eliminate the use of punitive and reactive responses to challenging behaviour. The approach therefore focuses on the use of positive proactive strategies to prevent behaviours occurring and enhance independence, choice and inclusion (Allen *et al.,* 2005).

Once ethical approval had been obtained, the researcher met with each of the unit managers to explain the nature of the study, share the research protocol and answer any questions. Based on the inclusion and exclusion criteria, managers were asked to identify service users who were eligible to take part. Regular contact was maintained between the researcher and unit managers to monitor progress in identifying participants.

Potential service user participants were identified and approached by the unit manager or a member of staff in charge who shared with them the information sheet (see appendix 9). The opportunity to clarify any aspects of the research was offered and two service users chose to meet with the researcher prior to consenting to take part in the study in order to clarify issues related to data storage. Once the service user appeared to have understood the details of the research they were asked if they wished to take part and informed consent obtained (see section 2.7.2; appendix 11). The service user was then supported by the unit manager or member of staff in charge to identify a carer and nominate a member of staff from their key work team that the researcher could interview about their experience.

Nominated carers and staff members were then contacted by the unit manager or member of staff in charge. They were provided with an information sheet (see appendix 10) and asked to return a signed consent form, with their contact details, directly to the researcher (see appendix 12).

Following analysis of the data collected from the first service user, carer and staff member, it was evident that data from each of the three participant groups was contributing meaningfully to the analysis. The researcher discussed this with her academic supervisor and considered it appropriate to continue sampling from each participant group in accordance with the principles of theoretical sampling (see section 2.5.4).

2.8.4 Description of Participants

This section provides a description of participants to enable the reader to understand the nature and context of the findings. In order to protect confidentiality participants have been provided with a pseudonym and identifiable information removed. Three service users consented to take part, each of whom nominated a carer and staff member who were also interviewed. Descriptions of the nine participants are summarised below:

Participant 1: Mel (Service user)

Mel was in her mid 30s and had been an inpatient on the assessment and treatment unit for seven months at the time of interview. She had a mild learning disability and additional diagnoses of personality disorder and epilepsy. Following a series of overdoses and admission to hospital, Mel was admitted to the assessment and treatment unit for one month. She was then discharged back to her staffed community house however was re-admitted to the unit two weeks later after several more overdose attempts. At this time Mel was detained under Section 3 of the Mental Health Act for a planned period of assessment and treatment in relation to her challenging behaviour. Mel remained on section at the time of interview and met the service criteria for delayed transfer of care indicating that she was ready for discharge but was waiting for an appropriate placement to be found.

Participant 2: Emily (Carer)

Emily was Mel's mother. She had cared for Mel in the family home until Mel moved into supported accommodation ten years ago. Emily maintained contact with Mel at least once

a week during her admission and lived in close proximity to the assessment and treatment unit.

Participant 3: Joanne (Staff member)

Joanne was a healthcare support worker who had worked with Mel since she was first admitted to the unit. Joanne was also familiar with Mel from her previous admission. Joanne had 31 years experience working with people with a learning disability and had worked on the assessment and treatment unit for 15 years.

Participant 4: Kat (Service user)

Kat was admitted to the assessment and treatment unit via the criminal justice system. She had been arrested and bailed to the unit following a violent and distressing incident in which she assaulted someone. She was later detained under Section 37 of the Mental Health Act. Kat had experienced one previous admission, four years earlier, which lasted approximately a month. Kat was in her mid 20s and had a mild learning disability as well as an autistic spectrum disorder. At the time of interview she was still on section and had been on the unit for one year. At the time of admission Kat had lived in her own home with her partner who passed away shortly after she was admitted. During admission Kat also experienced the loss of a number of other significant relationships. Kat was due to be discharged on section to a privately run secure hospital facility the week after her interview.

Participant 5: Natalie (Carer)

Natalie was Kat's mother. Natalie had cared for Kat in the family home until she moved into her own house approximately two years before she was admitted. Natalie remained involved in supporting Kat and her partner during this time and maintained contact with Kat at least once a week during her admission. Natalie lived in close proximity to the assessment and treatment unit. At the time of interview with Natalie, Kat had been discharged from the assessment and treatment unit.

Participant 6: Lucy (Staff member)

Lucy had worked on the assessment and treatment unit for 26 years as a healthcare support worker. She had supported Kat since her initial admission and was familiar with her from

her previous admission. At the time of interview with Lucy, Kat had been discharged from the assessment and treatment unit.

Participant 7: Alan (Service user)

Alan was in his 40s and had a mild learning disability. He had been an inpatient in the assessment and treatment unit for two and a half years before being transferred to another inpatient unit for an eighteen month period of specific therapeutic rehabilitation. When this contract of care came to an end Alan had returned to the assessment and treatment unit under Section 3 of the Mental Health Act. This was his third period of admission. At the time of interview Alan had been in the assessment and treatment unit for ten months, was no longer under section and was waiting for a suitable discharge placement to be found.

Participant 8: Sandra (Carer)

Sandra was Alan's sister. She had supported Alan during his previous community and inpatient placements. Sandra lived a short distance away from the assessment and treatment unit and maintained contact with Alan at least once a week.

Participant 9: Roger (Staff member)

Roger was a qualified nurse who had supported Alan since admission and throughout each of his previous admissions. Roger had 36 years experience working with adults with a learning disability, nine years of which had been on the assessment and treatment unit.

2.9 Procedure

2.9.1 Development of Interview Schedules

Semi-structured interview schedules were developed separately for service users and staff/carers. In line with the Grounded Theory philosophy (see section 2.4), these comprised broad stem open-ended questions to facilitate discussion and exploration of a wide range of aspects relating to service users' experiences from each participant's perspective. In addition, more focused and specific questions were used to encourage participants to elaborate on their responses (see appendices 13 & 14). Interview schedules were developed in consultation with the researcher's supervisors, based on the researcher's clinical experience and the aims of the study, as outlined in Chapter 1. In line with

recommendations from Young and Chesson (2006), visual prompts depicting emotions and key concepts within the interview schedule were made available to assist service users in engaging with the interview process. However, no service users required these.

The semi-structured interview schedules covered a number of areas including:

- The admission process
- The assessment and treatment process
- The recovery process
- The discharge process
- Service user involvement
- Environment
- Overall experience

Initial data analysis highlighted participants' repeated non engagement with questions relating to the physical nature of the assessment and treatment unit. In line with the principles of theoretical sampling (see section 2.5.4), prompts related to this line of questioning were subsequently removed from future interviews, however sufficient flexibility was maintained to allow participants to highlight this theme if it was relevant for them.

2.9.2 Interview Procedure

Upon receipt of consent forms, the researcher contacted participants and arrangements were made for interviews. Service users who consented to take part in the research were interviewed on the assessment and treatment unit. Each service user requested a member of staff to accompany them and this was arranged. Prior to interview, the researcher discussed with staff any communication needs the service user had and verbal communication was modified to an appropriate level for service users accordingly. Although visual communication support was available none of the service users required this. All carers were interviewed in their own homes. Two staff members were interviewed at their place of work and the other at a learning disability team base. Interviews ranged from 45 minutes to one hour 20 minutes. Time was allocated after the interviews for participants to debrief and ask any questions the interview had raised for them.

All interviews were audiotaped and transcribed within 1 week of the interview. Demographic information including age, gender, occupation, length of stay on unit and relationship to the service user was obtained at the start of the interview and documented separately from the transcript.

2.9.3 Data Analysis

Data analysis was conducted according to the Grounded Theory process described in section 2.5. Following verbatim transcription, each interview was read several times and initial open coding completed by hand. This enabled the researcher to become immersed in the data. Axial coding was then conducted alongside further memo writing to record the analytic process. Constant comparative analysis was employed and strategies for ensuring the quality of the research, as discussed previously, were adhered to (see section 2.6).

Service users', carers' and staff's transcripts were analysed separately to enable the researcher to explore similarities and differences between the themes generated from each group of participants. However, upon inspection of the data it was evident that the themes generated across the groups were similar and consequently categories and concepts were integrated for the purposes of final analysis and theory generation.

The researcher used the computer software package NVivo to aid the analytic process. The use of computer software in qualitative research has been criticised due to the risk that it reduces the researcher's closeness to the data and constrains analysis (Lee & Esterhuizen, 2000). The researcher's experience reflected this view and therefore transcripts were coded by hand as this was felt to achieve a more in depth analytic process. However, the researcher found NVivo to be a helpful tool in organising and storing the data, categories, concepts and memos constructed.

2.10 Researcher's Position

The researcher was a 29 year old white woman from a British working class background, employed as a Trainee Clinical Psychologist. She had a pre-existing interest in the research topic which had been stimulated by both personal and professional experiences and had a

motivation to enhance the quality of learning disability services such as those she had worked in or had personal contact with.

Having a sibling with a mild learning disability, the researcher had first-hand experience of the challenges facing individuals with a learning disability, and their families. In particular, her thinking had been influenced by the frustrations and inequalities she had observed in accessing appropriate healthcare support at times of difficulty. Her experience of this had been largely negative and she was aware of the possible influence this may have on her assumptions as she approached data collection and analysis.

Prior to commencing Clinical Psychology Training, the researcher worked in Learning Disability services. As an Assistant Psychologist she worked in a residential setting with a focus on implementing person-centred approaches to life skills teaching and transition planning for young adults with a learning disability who were moving from residential to community living. Following this, she worked in an assessment and treatment unit similar to those providing services to participants in the current study. Her research interests were borne largely from this clinical experience as she developed an interest in how service users and their families experienced admission to such units and the factors which influenced positive or negative outcomes of admission. The researcher was particularly interested in the systemic nature of the unit, thinking about relationships and patterns of behaviour, how these were managed and the impact they had on the admission and discharge experiences of service users.

The researcher chose not to undertake this research project within the Health Board in which she had been previously employed. The researcher was aware that, in part, this was due to a belief that the service users and family members would report mainly negative views on the unit as a result of negative opinions she had witnessed in the past. The focus of the current research was driven by a desire to give service users a voice and a platform from which their stories and those of their families, could be heard; whether positive or negative. The researcher therefore remained mindful of her assumptions throughout the data collection and analysis process in order to minimise any bias in her interpretation.

The development of the specific research topic was shaped by discussions with the researcher's clinical and academic supervisors, as well as by related issues in the media

and political spheres. Specifically, the researcher's interest in exploring service users'
experiences was fuelled by a documentary and subsequent government investigation into
abuses in inpatient services for people with a learning disability. In particular, the
researcher became interested in what it was like to be resident on an inpatient unit,
particularly for a longer period of time. The researcher recognised her assumptions
regarding this and the potential influence of these assumptions was monitored through
regular supervision and the use of a reflective diary (see appendix 4 for extracts).

CHAPTER 3: RESULTS

3.1 Chapter Overview

This chapter presents the key findings and themes from the Grounded Theory analysis of the data collected from the nine participants. These themes are arranged into core concepts, categories and sub-categories. Within the text, and for the purposes of diagrammatic representation, **CORE CONCEPTS** are written in bold uppercase font, **categories** are written in bold lowercase font and <u>sub-categories</u> are written underlined in lowercase font.

Five **CORE CATEGORIES** were generated from participants' narratives about service users' experiences. Figure 3.1 provides a summary of the **CORE CONCEPTS** and **categories** generated from the Grounded Theory Analysis. Each **CORE CONCEPT** along with its related **categories** and <u>sub-categories</u> is then presented with a diagrammatic representation and definition, followed by discussion and illustrative quotes from the interviews.

Following a detailed description of the results a diagrammatic model of the resulting Grounded Theory is presented in Figure 3.7 in order to demonstrate how the **CORE CATEGORIES** are linked. This is further explained in section 3.7.

To protect anonymity each participant has been allocated a pseudonym and identifiable information has been removed or changed.

Figure 3.1: Diagrammatic Summary of the Grounded Theory Analysis

THE COURSE OF ADMISSION	SENSE OF SELF & CONNECTEDNESS	SENSE OF AGENCY	CREATING SAFETY & PROTECTION	UNDERSTANDING & MEANING
Being Admitted	Identification with Learning Disability	Autonomy & Freedom	Vulnerability & Need for Protection	Sharing Understanding
Assessment and Treatment	Relationships with Staff	Externally Imposed Constraints	Ensuring Service Users' Safety	Understanding the Service User
The Discharge Process	Relationships with Family	Service User Inclusion and Involvement	Feeling Safe	Making Sense of Change
	Valued & Meaningful Sense of Purpose			

3.2 Core Concept: The Course of Admission

This core concept refers to service users' experiences of the different procedures and stages of their admission and includes three categories: **being admitted, assessment and treatment** and **the discharge process**

Figure 3.2: Diagrammatic Summary of Core Concept **THE COURSE OF ADMISSION**
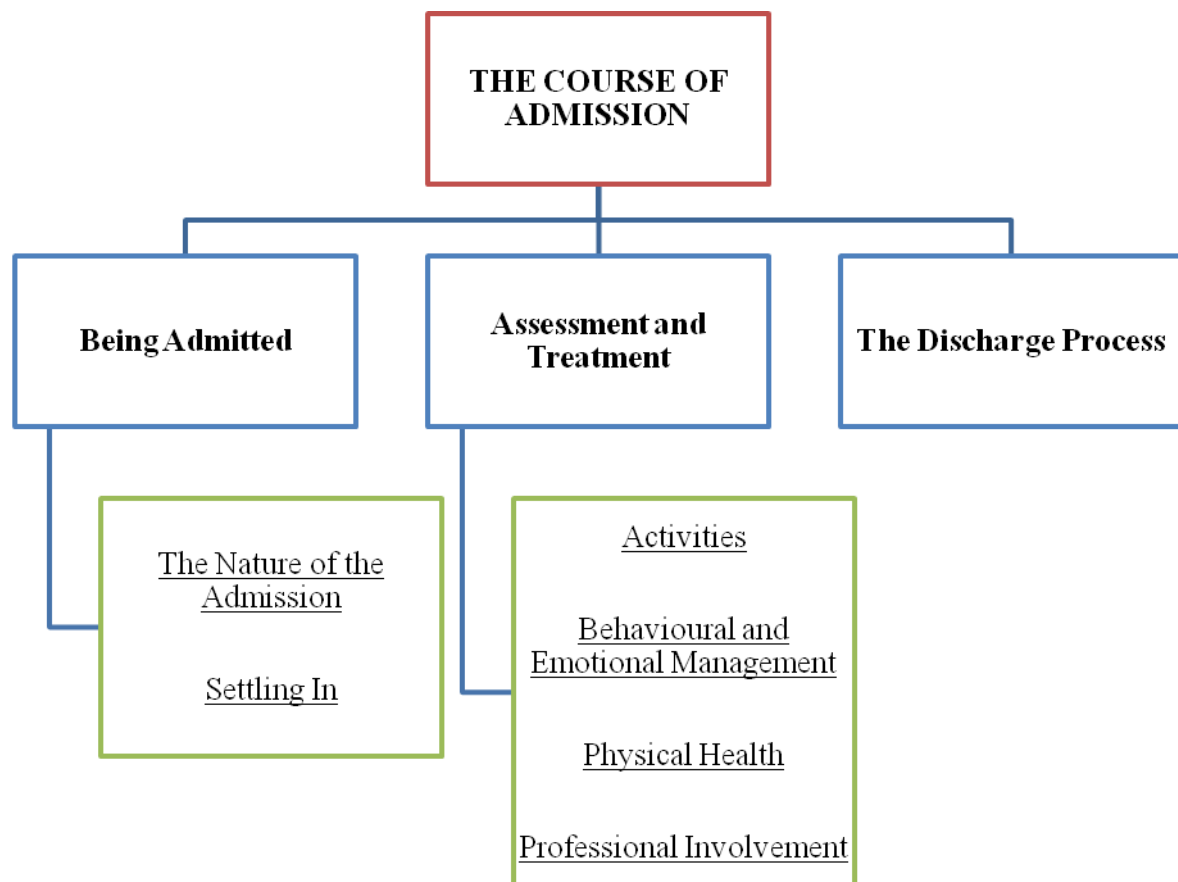
3.2.1 Category: Being Admitted

Participants talked about how service users experienced the process of **being admitted** in relation to <u>the nature of the admission</u> and the necessity for a <u>settling in</u> period.

3.2.1.1 Sub-Category: The Nature of the Admission

<u>The nature of the admission</u> captures the beliefs service users held about the reason for their admission:

"I had to come back here coz I was on a waiting list." (Alan, service user)

"The police brought me here ... To punish me for what I did" (Kat, service user)

"Because I took too much overdoses and I was in hospital all the time ... the staff were worried about me and the social worker was worried about me ... [they wanted] me to be in a safe place." (Mel, service user)

The beliefs service users held about the reason for their admission appeared to have contributed to their views of the unit and feelings about their admission:

"Alan saw [his first admission] as a punishment. Basically he thought 'they've taken me away from my family, they're punishing me because I am out of control. Because I have done bad things I am here.' That's how he saw it, as a punishment." (Sandra, carer)

"We'd explained to Kat that this time it wasn't her choice to leave. That she could not leave the assessment and treatment unit. She was there...and her view was I'm a prisoner then." (Natalie, carer)

All of the service users had experienced previous stays in assessment and treatment units, which also contributed to their views on admission:

"Kat hadn't liked the experience there the first time because she was a totally different girl the first time. She was very angry when she went into the assessment and treatment unit and obviously it was a different admission." (Natalie, carer)

"I didn't want to be here because I been here before and I didn't like it." (Kat, service user)

"There were suggestions that it wasn't a good idea for Alan to come back to the assessment and treatment unit by the community nurse. She said that she felt this would be detrimental because Alan would always see this as a stepping stone, [he would think] 'if this doesn't work out I can go back to the assessment and treatment unit.'" (Sandra, carer)

The familiarity service users had with the unit and staff, as a result of having previously been admitted on the unit, was also believed to influence how they experienced their initial admission:

"Familiarity [is very important in making the initial admission positive]. Not just the building but people ... I think there was only maybe two members of staff out of the whole team that Alan didn't know" (Roger, staff member)

3.2.1.2 Sub-Category: Settling In

For some services users the initial process of admission was described as being traumatic, scary and unsettling:

> "[The events surrounding Kat's admission] were horrendous ... there were police cars, paramedics, ambulances, dogs ... It was horrendous, absolutely horrendous ... someone asked my sister 'what's happening, what's happening?' and she said 'they're filming an episode of The Bill'. Because that's what it was like. It was awful ... [The initial process of Kat being admitted] was quite traumatic as you can imagine." (Natalie, carer)

> "[When I was first admitted it was] scary ... I stayed in my room for hours. Couldn't come out ... I didn't want to be here." (Kat, service user)

> "[When I first arrived here] I wasn't settled. I was getting angry, I escaped a few times ... It makes me feel unsettled, sharing a new place with other patients." (Mel, service user)

In response to the trauma and anxiety of admission, and in relation to the benefits of service users being familiar with the unit and staff noted above, participants described the importance of a settling in period:

> "It took a while to get used to the new patients and staff" (Mel, service user)

> "Alan needs to settle back in and we all said it's going to be a honeymoon period for a couple of weeks and then he's going to deteriorate." (Sandra, carer)

> "When Mel was first admitted I think like all the patients [when they first] come, they're very anxious, but after the initial coming in, we'll talk to them, we'll show them where they're going to be staying, we'll introduce them, we'll try and put them at ease and make them as welcome as possible because it's daunting for them obviously. And Mel was fine." (Joanne, staff member)

3.2.2 Category: Assessment and Treatment

Service users' overall experience of **assessment and treatment** is understood in relation to four sub-categories which highlight key factors that contributed to **assessment and treatment** procedures: activities, behavioural and emotional management, physical health and professional involvement

3.2.2.1 Sub-Category: Activities

Activities on the unit formed a positive component of the experience of admission for service users:

> *"Well staff find things for you to do ... they got one member of staff and she likes making cards. She likes making cards and she'll show you what to do, you know. She used to be a learner how to show you how to make cards. Then when you know how to do it, I went for my own card maker kit, you know."* (Alan, service user)

> *"The activities are good. Do drawing, arts and crafts ... We do jewellery making, card making, sewing, play games connect 4 and bingo ... Go out in the garden ... Sometimes I play games."* (Mel, service user)

Furthermore, outings off the unit provided particular enjoyment for service users:

> *"I think going out, when he knows that he's going out especially, is the highlight of Alan's day."* (Roger, staff member)

> *"Staff took me out for a run in the bus, down [the beach] ... it was comforting, seeing all the different areas, where I used to go."* (Kat, service user)

> *"Mel loves going out. She doesn't mind walking, catching a bus, anything, as long as she's out she's happy."* (Joanne, staff member)

Carers and staff recognised the necessity for structure and routine within the daily activities that were organised for service users:

> *"I think they have got structured days, Alan needs structure, he needs routine and he has got a timetable,"* (Sandra, carer)

> *"[All service users] had a timetable every week and they were different because we have other patients that we have to fit everybody in. So Kat's timetable we tried to stick to it as much as we could to the times and sometimes it wasn't possible and that was a big issue because when you tell her you're going out at 10 o'clock, if you went out at half past she'd be flaming bezerk by half past."* (Lucy, staff member)

However, participants noted the disappointment service users experienced when planned activities had to be cancelled:

> *"Over the years when Alan's been with us he's had a lot of disappointments [with activities having to be cancelled]."* (Roger, staff member)

"Staff in charge will say 'we'll have to cancel your home visit [because staff cannot take you and pick you up]' ... it feels upsetting, you know. You think you've been good all week kind of thing and you thinks you be going home, see." (Alan, service user)

Difficulties in providing activities and sticking to plans were attributed to the unpredictable nature of the unit and the limited staffing resources available to meet service users' needs:

"I know staff haven't always got the time [to take Mel out] ... and they say when something happens in the unit they have to be there ... they can't [give her more time] because they've always got emergencies coming in or somebody kicks off on the unit." (Emily, carer)

"We're an eight bedded unit we tend to work 4 staff. If we have someone in who is exceptionally challenging and something, and they have an aggressive outburst, there's no way I can turn round, if we have two people dealing with that person, and have one person take Alan out and leave one person dealing with the other six." (Roger, staff member)

"Sometimes we go out in the morning or the afternoon if staff are not busy ... we usually go out in the afternoon instead of the morning because staff are busy in the morning." (Mel, service user)

Participants also emphasised the potential for service users to engage in challenging behaviour when activities were cancelled or when they were not given the attention it was felt they needed:

"I know some staff in the past haven't got time [for Alan] and I think well you're actually asking him to play up. He wants a bit of attention so if the only way he's gonna get it is to have a blip then he's going to have a blip isn't it you know. Which is what would happen." (Roger, staff member)

"Mel doesn't like [activities being cancelled]. So I'm thinking then she's kicking off because she's thinking, 'I'm going to get a bit of attention here.' I think that's the way she behaves." (Emily, carer)

3.2.2.2 Sub-Category: Behavioural and Emotional Management

A range of strategies were identified which contributed to managing service users' challenging behaviour and emotional distress. These seemed to form another important aspect of the **assessment and treatment** process.

When discussing what service users had found helpful during their admission, they unanimously expressed positive opinions about 'talk time' with staff as a way of providing comfort and helping them to manage their own behaviour:

"(Researcher): What things helped you to be able to 'be good and not get into trouble'?
(Participant): Well I talked to member of staff, I talked to a member of staff." (Alan, service user)

"Some of the staff comfort me ... They talk to me and hug me" (Kat, service user)

"Staff talked to me about trying not to run away or take overdoes." (Mel, service user)

'Talk time' was identified as being a proactive strategy that staff used within the Positive Behaviour Support (PBS) approach adopted by the assessment and treatment units. Where behaviours escalated however, the use of restraint was described:

"We've got the same [approach to behaviour support] for everybody. There's primary, secondary and reactive and we've got the positive behaviour management and that. So when you think Kat's going off baseline you start giving the talk time blah blah blah. And if it went to the next thing then, only once or twice I think she had to be restrained and she had her things taken out of her room because she was throwing them" (Lucy, staff member)

"We restrained Mel to be honest, because she was much angrier than I've ever seen her yesterday morning ... it was easier to sit her down in a seated restrain just to keep her calm, talk to her, I felt" (Joanne, staff member)

Participants also talked about the use of praise and rewards given in response to service users managing their own behaviours or emotional distress:

"[Going shopping] will be an extra outing. Which is like a reward for Alan cleaning out his wardrobe and he's full of it then." (Roger, staff member)

"I say to Kat 'I'm so proud of you coz you've done this now, I'm so proud of you coz you're moving on now" (Natalie, carer)

"I do tell Mel I'm very proud of her, because she's learning to deal with her anger better." (Joanne, staff member)

Medication was described as having been used to help manage service users' physical, emotional and behavioural difficulties. Mixed views were expressed by participants about its use however:

"Sometimes Kat wouldn't get out of bed and she'd stay there. I could see that when she was really really anxious, her hands used to shake. And when I thought she was going to blow her hands would start shaking and that's when I say 'do you want a tablet?' [and she'd say] 'Yes please.'" (Lucy, staff member)

"Mel will always need help, but I don't think it should be through medication. Medication for her epilepsy yes, and maybe carry on the antidepressants, I don't know. I'm very much against those as well, the antipsychotic, but she's been taken off that, but I don't believe it would work for her." (Emily, carer)

"New tablets sometimes makes me drowsy or they don't work ... it's frustrating ... [the psychiatrist tells me] 'It's good for you. They keep you calm, they keep your OCD levels down.'" (Kat, service user)

Assessment and treatment also incorporated therapeutic input, however this did not always match service users' expectations of what therapy would be:

"Kat kept saying 'they promised to do me anger management'. Well of course they were doing it but at a level that she could cope with ... she never saw that as a therapy like you or I would understand that they're talking to me but I'm having treatment here. Because it's talking therapy and you're treating somebody as you're talking to them. Talking them around things and saying to them 'yeah but that happened because of this and that's why you're feeling like that'. She didn't understand any of that at all so she saw it as they're doing nothing for me here." (Natalie, carer)

3.2.2.3 Sub-Category: Physical Health

This sub category refers to the <u>physical health</u> monitoring and treatment that service users received as part of their **assessment and treatment:**

"All the patients, they have a head to toe of everything. Sometimes they might come in and they're playing up but all they've got is toothache, and service users get agitated with a toothache and staff don't realise lots of things. So we usually do a head to toe on them first." (Joanne, staff member)

"[I've seen] the dentist. Go to the dentist weekly, went yesterday for a check up and had my teeth brushed ... And I take ear drops because I have an infection in my ears and I might have to go to the hospital. And went to the chiropodist but there's one here now next month." (Mel, service user)

"We still assess his mental health and everything else like his weight. Alan's on a reducing programme now the dietician saw him this morning and she said he'd lost a few pounds since she saw him last" (Roger, staff member)

3.2.2.4 Sub-Category: Professional Involvement

Involvement from professionals outside of the unit was also identified by participants as part of the **assessment and treatment** that service users received:

> *"The social worker drew up this plan and the psychologists and psychiatrists and the specialist behaviour team were involved, I think [unit staff] all know now how to approach Mel in a different way and that seems to be working ... with the help of everybody putting in their input and getting to know what makes Mel, service user tick really."* (Emily, carer)

> *"[I see] the psychiatrist."* (Kat, service user)

> *"I know Kat had art therapy ... the psychologist and the art therapist"* (Lucy, staff member)

> *"Carley comes on a Wednesday, the occupational therapy assistant, and we do arts and crafts ourselves when Carley's not around."* (Mel, service user)

3.2.3 Category: The Discharge Process

Each of the service users had experienced an extended period of admission on the unit as a consequence of difficulties in planning their discharge and limited availability of appropriate placements:

> *"I've been here since March and I don't know when they're going to find me a place to live ... they said they didn't know how long it would be for a place to come up because they're short at the moment for houses."* (Mel, service user)

> *"All Alan needs, which is easier said than done, is a house with the right management. If you could actually put the way we manage him into a house with one maybe two other people, he would be very happy. But because of all the different rules they've got for their registration and everything, they can't do it see."* (Roger, staff member)

Participants described the implications for service users of having been on the unit for long periods of time. These included service users no longer having activities to do, becoming too comfortable and not wanting to leave:

> *"Now the staff know Alan he's not there for assessment ... he's not having cookery lessons or being assessed. So there's a lot less for him to do ... I wish the staff could do more with him."* (Sandra, carer)

"I think [the unit manager] said the same, he said the sooner I get Mel out of there the better. Because I think she will become institutionalised if she stays there any longer, and I don't want that for her … She's been there for too long I think, and I don't want her to get comfortable there, because it's not the type of place that I want her to be, not all the time." (Emily, carer)

"We have service users who have been here a while and they're 'blocking beds' we call it, because there's nowhere for them to go. They've had the treatment and assessment, but they're particularly difficult in their behaviours to manage, and providers won't accept them then for whatever reason. It could be money, it could be whatever, but sometimes they can be here too long and they get too happy here [and they don't want to leave]." (Joanne, staff member)

In response to the idea of discharge, service users were described as being ambivalent or reluctant about leaving the unit:

"Alan likes being with us so, although every now and again he'll say 'I'm waiting for a new home I can't wait to go to a new home' [he'll also say] 'I don't want to leave here, I'll miss you all.'" (Roger, staff member)

"I'm patient waiting. I don't mind waiting for a place to come up … When it comes to move I won't want to move" (Mel, service user)

"Before Kat left she didn't want to go, she wanted to stay here, she was really upset … She started crying, upset [she said] 'I miss you all, I don't wanna go, you understand me.'" (Lucy, staff member)

3.3 Core Concept: Sense of Self and Connectedness

This core concept refers to how service users viewed themselves in relation to other people on the unit; their sense of connectedness with other service users, staff and their families; and how this affected and was affected by their experience of admission. Four categories were constructed which capture the factors which influenced service users' **SENSE OF SELF AND CONNECTEDNESS: identification with learning disability, relationships with staff, relationships with family** and **valued and meaningful sense of purpose.**

Figure 3.3: Diagrammatic Summary of Core Concept **SENSE OF SELF AND CONNECTEDNESS**
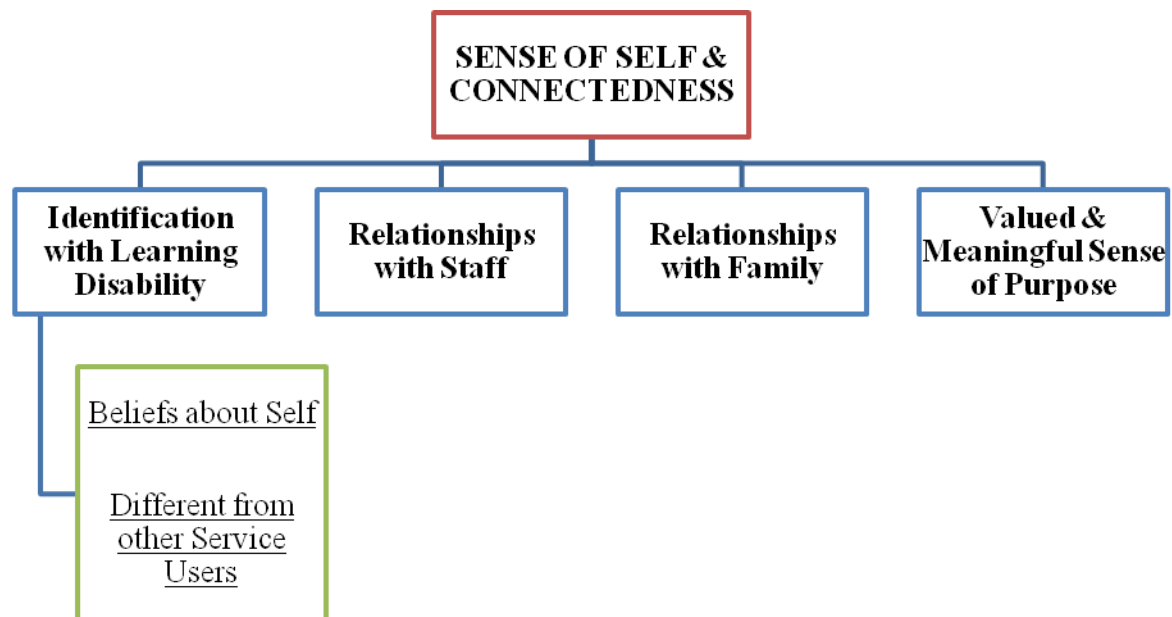
3.3.1 Category: Identification with Learning Disability

Service users' **SENSE OF SELF AND CONNECTEDNESS** appeared to be influenced by their views on people with a learning disability and their personal identification with this label. This category comprised two subcategories: beliefs about self and different from other service users.

3.3.1.1 Sub-Category: Beliefs about Self

The sub-category beliefs about self encompassed a number of different aspects of service users' beliefs about themselves. Within this sub-category participants described service users as holding strong beliefs about themselves as being 'normal' and not acknowledging their learning disability:

> *"Alan has not got affinity with people of his own mental ability ... Alan will not agree that he's not normal in any way."* (Sandra, carer)

> *"Kat's always wanted to be, what she calls 'normal' [she says] 'I don't want to be here, I don't want to be in this unit, I wanna be normal, I want to be out in the street and do what other people do.' ... She doesn't see her disability."* (Natalie, carer)

"Kat didn't think she wasn't normal, or different. She hated, if somebody called her a spaz or anything like that she'd go mad. She would kill you coz she'd go ballistic." (Lucy, staff member)

In addition, some service users' views about their need for support were influenced by their beliefs about themselves as being capable and independent:

"Kat didn't like the fact that [staff] would have to come home with her and stay with her ... [She says] 'I don't wanna be in a house where I got staff. I don't want people telling me what to do'. But what she doesn't understand is she's not capable of doing it on her own." (Natalie, carer)

"And when they were doing Mel's hair [she would say] 'I don't want this, I can do this myself.'" (Emily, carer)

3.3.1.2 Sub-Category: Different from Other Service Users

Participants also talked about services users' views on people with learning and physical disabilities and of themselves as being <u>different from other service users</u>. Some participants talked about the negative views service users held about people with disabilities:

"There's no understanding with Alan of disabilities. He's not very understanding of peoples' disabilities, he's not very patient ... So he's not understanding of other peoples' conditions or disabilities at all ... Alan's terminology, 'They're not right in the head,' or, 'They a bit silly, they childish,' he just sees them as completely different to him and not accepting at all." (Sandra, carer)

"Screaming, shouting, wake me up in the middle of the night and first thing in the morning ...Only two other patients I got on with. The rest have been noisy, difficult ... I'm more quiet than they are ... [The people I find most difficult to get on with] dribble, spit, scream ... pinch food, not normal people." (Kat, service user)

These views led to some service users viewing themselves as 'better' than other service users:

"[Alan sees himself] the old fashioned way I think, a bit of a top dog ... he thinks he's better [than other service users]" (Roger, staff member)

"I think Mel thinks that [other service users] are less than her, does that make sense? Less as in she's more intelligent. Like they've got more of a learning disability than her, that's what I think." (Joanne, staff member)

Furthermore, some service users seemed to find it difficult to relate to and develop relationships with other service users, which sometimes resulted in them isolating themselves:

> *"[I watch] TV in my bedroom to [stay away from other people]"* (Kat, service user)

> *"I keep myself to myself but some patients don't talk and if there's noises and stuff like that I just keep myself to myself, you know."* (Alan, service user)

> *"When Alan was in last time, we had two people with Downs in, and Alan spent very very little time in the main living room because he didn't like being in with them."* (Roger, staff member)

Carers also described the differences between service users and the inappropriate mix on the unit which sometimes resulted in negative consequences such as service users copying behaviours:

> *"It was not the right place for Kat; there was not the right mix of people."* (Natalie, carer)

> *"Mel shouldn't really be there because she's not as bad as the other people that are there, and I think it's having an impact on her, that if they start to scream and shout then she will do the same ... and Mel's never behaved like that. I think it's having an impact on her."* (Emily, carer)

3.3.2 Category: Relationships with Staff

This category refers to the closeness and significance of service users' relationships with staff, which may be seen to have contributed to service users having a sense of connectedness with staff on the unit. Many participants characterised the nature of service users' **relationships with staff** as being similar to those experienced between friends or family:

> *"I think Alan probably sees me as a big brother or father type figure ... I think staff have become his extended family over the years."* (Roger, staff member)

> *"Well, me and Roger put our hands together like that (bumps fists together) and shake hands ... I'll miss Roger a lot. He's been like a friend."* (Alan, service user)

> *"Kat liked to be in with the staff, that's what she wants is to be normal ... she wanted to [join in with staff's conversations] because she wants to be like your friend."* (Lucy, staff member)

Whereas service users saw themselves as <u>different from other service users</u>, some participants described service users as feeling similar to or like staff:

> *"Alan sees himself as one of them [staff] really, I suppose ... [he thinks] he's the same as them. I think he sees them as friends."* (Sandra, carer)

> *"Mel's very caring and loving with all the other patients. But it's like she's the staff and they're the patient ... She's more on [staff's] level, that's what Mel thinks."* (Joanne, staff member)

> *"And I said to staff yesterday 'can't you train me to do the medication? I won't take any more overdoses. In three years time I can be a member of staff here.' Staff said 'You'd be a wonderful member of staff.'"* (Mel, service user)

For one service user however, not all **relationships with staff** were experienced positively and sometimes resulted in her isolating herself on the unit:

> *"Kat took a dislike to a few staff and [it was] terrible. Terrible."* (Lucy, staff member)

> *"A nightmare with horrible staff, but nice with nice staff. [When horrible staff are working I feel] depressed. I stay in bed so I don't have to see them"* (Kat, service user)

3.3.3 Category: Relationships with Family

This category highlighted the impact that admission to the unit had on service users' relationships, contact and sense of connectedness with family. Service users' **relationships with family** were reported to have been disrupted upon admission by the traumatic processes of separation from and perceived rejection by family:

> *"I think first of all it was so awful for Alan because he'd never been from home."* (Sandra, carer)

> *"[Kat thought] somebody wanted her put back in ATU. My husband and I were the bad guys at the time because she saw we were agreeing to this ... She sort of understands it but she also says you've ruined my life, you've taken my life away from me."* (Natalie, carer)

> *"Mel [says] 'You've put me here in here, it's your fault I'm here. I want my stuff that I left in your house; I want you to bring it over here. I'm not coming there on Sunday,'"* (Emily, carer)

One service user described the 'living hell' of being separated from her family and her loss of significant relationships during her admission:

"It's been a living hell for a year ... Being in here, lonely, my partner died and then my dad died." (Kat, service user)

Ensuring contact with family was therefore recognised as important in order for service users to maintain a sense of connectedness within significant family relationships:

"Mel would like to see me more and I'd like to see her more, but the situation is that I can't. I can't just get two buses up there every day because I don't have the money some days to go up there." (Emily, carer)

"We'd see Kat every week at the meeting so we saw a lot of her. She phoned three times a week. And we had a lot of contact." (Natalie, carer)

"I see my parents every other weekend. See my dad every Sunday and see my mum when she can because she works long hours. I wish I could see them twice a week." (Mel, service user)

Facilitating inclusion in family events appeared to be particularly important for two service users where significant family events took place:

"Alan's father is in hospital at the moment. He's actually going to see him this afternoon so he should be there now ... his sister has been going to visit the father every night and she'll ring Alan to let him know how he is." (Roger, staff member)

"There was the trauma of Kat seeing her partner's body. Thank god I had a good relationship with the staff there because we all sat down and we said 'look, she'll have to see his body otherwise she'll think we're trying to keep her away from him and we're lying to her.' So two of the staff, her step-dad and myself took her down to view his body which was really difficult for her ... the unit facilitated everything then for her to be able to be part of the funeral." (Natalie, carer)

The importance and significance of service users' relationships and connectedness with family was further highlighted by their ongoing desire to return home or remain close to family following discharge:

"Alan wants to be home with the family. If you really ask him he'd say, 'I want to live with my sister and her husband,' I honestly believe that." (Sandra, carer)

"I think I've got a placement coming up but I hope it's not far away and I'll take it, you know." (Alan, service user)

"I miss mum and dad a lot. I've been away from home from them for a long time." (Mel, service user)

3.3.4 Category: Valued and Meaningful Sense of Purpose

This category refers to the impact that having a role and a purpose on the unit had on some service users' sense of value and responsibility. Some participants described service users as having a meaningful role in helping staff and looking after other service users:

> *"There are people there that Mel reads stories to and looks after. She sees that as her being the protector, mothering them and looking after them."* (Emily, carer)

> *"You know, if there's some patients playing up and staff can't do it, they'll ask me and I'll try to help out"* (Alan, service user)

> *"I help with the laundry, I help with the patients ... I help them [staff] with the laundrette with the bags. And I help go over to help them empty the bins into the big bins. I help put the laundry away in that part there."* (Mel, service user)

One service user was also reported to have specific jobs that he carried out on the unit which gave him a sense of responsibility and the feeling of being trusted:

> *"I tell you what's fantastic is that they've actually given Alan responsibility, and that is brilliant. They gave him – I don't know if he does it anymore, he used to do – the mail. He used to sort the mail and take it round ... he felt he had a role.*" (Sandra, carer)

> *"It's good to come off section you know, and you can prove to staff that you can do more and be trusted and like I got one job where I go down the storage room and I keeps sheets and towels and things like that. Staff used to stand by my side and watch me doing it but I don't have that no more."* (Alan, service user)

3.4 Core Concept: Sense of Agency

This core concept refers to service users' experiences of being able to act from their own volition by having control and responsibility over their lives during admission. This concept consists of three categories: **autonomy and freedom, externally imposed constraints** and **service user inclusion and involvement**.

Figure 3.4: Diagrammatic Summary of Core Concept **SENSE OF AGENCY**
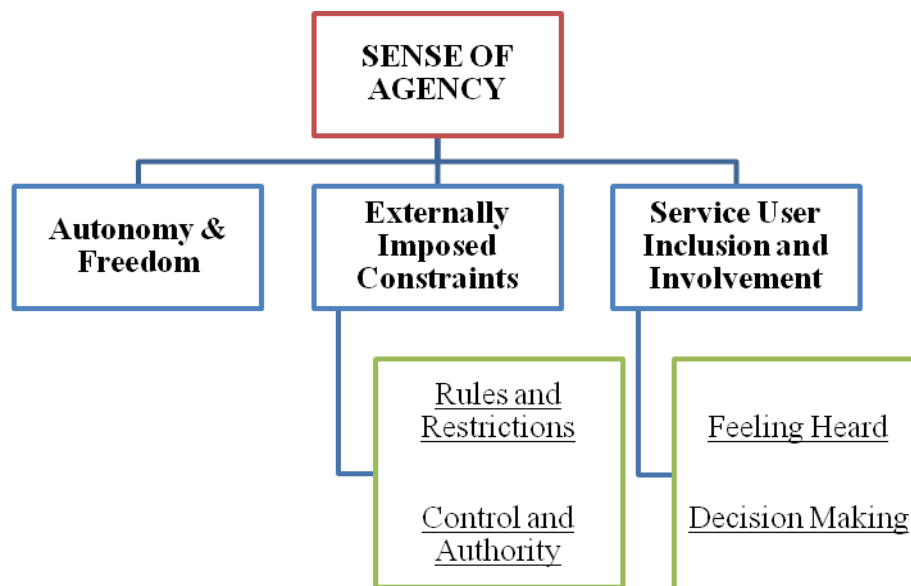
3.4.1 Category: Autonomy and Freedom

Participants described the impact that being on the assessment and treatment unit had on the level of autonomy and freedom service users experienced. One service user described her negative experience of losing some of the **autonomy and freedom** she had when she had been living in the community, as a result of being on the assessment and treatment unit:

> *"I haven't got the life I had before I came in here ... no partner, no cats, no freedom, no on my own in the house, no house with just me and my partner and the animals, not allowed to go out on my own, people on my back ... the life I had, I may as well be in prison."* (Kat, service user)

Another service user also described his experience of lacking the control and freedom to determine his own relationships, and of being advised by ward staff to be friends with another service user despite his not wanting to:

> *"I had one ward round the other day and the Doctor said 'you be friends to this man coz he's got an illness, and he likes to be friends all the time' and they said to me 'you will change your mind and be friends.' I said 'I don't know really I should do that.' [but] I said 'alright I'll give it a go."* (Alan, service user)

For another service user however, admission provided respite from a level of independence which she had found difficult to manage in the community:

> *"I don't like cooking on my own. And I don't like having baths on my own … I don't like being on my own. I don't like living on my own because it's not the right place for me anymore. And I don't like cooking either, or ironing."* (Mel, service user)

In relation to discharge planning and hopes for the future, service users' wishes around autonomy, freedom and independence were also illustrated:

> *"They've got to find me 24 hour care [in my next placement]."* (Mel, service user)

> *"When Alan moves on he'll probably be even happier because he'll have even more freedom."* (Roger, staff member)

> *"I'd like to have my life back, like before I came in here…gone awful. No freedom … I hope [I get more freedom when I leave] but got a gut feeling to say no. I want a house of my own."* (Kat, service user)

3.4.2 Category: Externally Imposed Constraints

Externally imposed constraints relates to the <u>rules and restrictions</u> that were perceived to be in place on the assessment and treatment unit, and service users' experiences of staff being in a position of having <u>control and authority.</u>

3.4.2.1 Sub-Category: Rules and Restrictions

Restrictions and limitations on what service users felt they were allowed to do and have were evident throughout participants' narratives. One service user described his positive view of being on section:

> *"[Being on section] holds you in place…it holds you in some place to take care of you kind of thing, you know"* (Alan, service user)

However, participants also described the constraints and restrictions on service users' liberty that being on section resulted in:

> *"[Being on section] means I can't go out on my own, I have to go out with staff."* (Mel, service user)

"[To Alan coming off section meant] 'I'm free, I don't have to be on section'." (Roger, staff member)

When service users came off section some continued to have staff accompanying them when they went out. This presented another perceived source of restriction on what they were able to do, as described by one service user:

"I came off section and I have one to one [support from staff]. And other service users are all one to one down there too. So say now this morning there were three staff on and three staff in the afternoon, that means we can't go out." (Alan, service user)

Staff and carers described boundaries that were in place on the unit which sometimes restricted what service users could have:

"Boundaries all the time, that's how we work on this assessment unit, you've got to have boundaries but fairness, always fair." (Joanne, staff member)

"Alan does know that there are boundaries and he can't have everything he wants." (Sandra, carer)

In particular, boundaries and restrictions were described in relation to access to money:

"If I've taken Mel to the shops and I've done Christmas shopping, then you have to use your initiative. Tell her 'we've got 20 pounds or 40 pounds, that's all we've got, and we've got to get this, that and the other.' You have to be firm and fair with service users; don't give them too much or give them the 100 pounds when they can only spend 40." (Joanne, staff member)

"At the moment Alan's got money in his savings and he'll say 'get my card, I'll draw my £40 out.' I'll say 'no, you don't need it.' Because we're only allowed to hold £30 in the tin on the ward, our budgeting thing." (Roger, staff member)

Rules around how the assessment and treatment units were run and how service users were allowed to spend their time were also described:

"I'd like to get up at 2 o'clock in the afternoon ... [but I'm] not allowed to stay in bed all day." (Kat, service user)

"I stick to the rules, we have a drink of tea at certain times and lunch at certain times and tea at certain times and supper at certain times…I'm used to it now, I'll stick to it wherever I go now I'm used to it. And I eat healthily now. I stick to the rules…We have to go to bed at certain times, 9.00 or 9.30. We're not allowed to stay up till 10.00 because it's the rules. That's not a good rule. We have to be in bed by 10.00." (Mel, service user)

Mixed feelings were expressed about how service users experienced these <u>rules and restrictions</u>. One participant described the positive experience a service user had as a result of having boundaries in place:

> *"I think Mel feels safe here and I think she likes the fact that she's got boundaries and people are being professional with her, I think she does like it."* (Joanne, staff member)

However, for other service users the experiences of rules and restrictions were described negatively:

> *"I can't do whatever I want. I didn't have rules in mine and my partner's house"* (Kat, service user)

> *"[Kat saw it as] staff were nasty to her. You know, they'd stopped her doing something probably that she wanted to do."* (Natalie, carer)

> *"Staff will say to Alan, 'No, you're not having it,' give him an explanation. They know he's going to come back [to me] and say, 'I hate staff. They said no to this.'"* (Sandra, carer)

3.4.2.2 Sub-Category: Control and Authority

This sub-category relates to participants' perceptions of service users feeling that staff and carers had <u>control and authority</u> over what they did:

> *"[Alan sees it as staff are] telling him what to do and ruling him.'"* (Sandra, carer)

> *"Kat would see [people telling her what to do] I think, as them controlling her life."* (Natalie, carer)

> *"Mel doesn't like [staff being strict] because she sees that as them being the boss."* (Emily, carer)

One staff member reported that what service users could do and have had to be 'negotiated'. Furthermore, the outcome of this was sometimes determined by staff and carers' views about whether the service user 'needed' what they were asking for:

> *"Everything that happened with Alan or his family was always negotiated through the primary nurse ... if he wanted anything and he wanted to go anywhere it would have to be negotiated through me ... [sometimes] Alan wanted something see and I said 'no you can't have that' ... Because he'll say 'get my card, I'll draw my £40 out.' I'll say 'no, you don't need it.'"* (Roger, staff member)

In addition, the staff member also described the belief this service user had that staff would 'enforce' restrictions:

> *"I've said to Alan 'now you're not going out today because you're not very happy.' [and he has said] 'I am I'm fine.' And I know he's not just by looking at his face. I say 'when you tell me what's wrong I'll think about you going out.' … And more often than not then, because he knows that I will enforce that he doesn't stay in his room all day, we'll get to the bottom of the problem."* (Roger, staff member)

3.4.3 Category: Service User Inclusion and Involvement

This category incorporates factors that were constructed in relation to how service users' **SENSE OF AGENCY** was influenced by their inclusion and involvement in aspects of their admission and discharge. This category captures service users' experiences of <u>feeling heard</u> and of being involved in <u>decision making</u> around their care and discharge planning.

3.4.3.1 Sub-Category: Feeling Heard

Service users identified a number of verbal and non-verbal strategies that they employed in order to make their opinions known:

> *"I do come out and I tell staff off. I say 'you're wrong what you're doing, stopping my home visit. I worked all the week and I thought I was gonna go home visit and you've stopped it.'"* (Alan, service user)

> *"[When I'm not happy about something] I go mad."* (Kat, service user)

In order to feel heard and get what they wanted service users were also described as needing to be persistent:

> *"If Alan says, 'I want it, I want it,' and if he keeps on for several months, he really wants it."* (Sandra, carer)

> *"What Mel does is if she can't get what she wants from here, her mum and dad phones twice a day so she'll get them to come out of work and do it or something, so she gets what she wants in the end."* (Joanne, staff member)

Carers' views of their role in advocating for service users, and their need to speak up for them and do things in their best interests, were acknowledged and illustrated by carers in these quotes:

"As long as I'm here as Mel's mother I will always look after her and always speak for her, and I don't want her just left and put on tablets just to keep her quiet and things like that." (Emily, carer)

"Everything was done in Kat's best interests ... [however] the mental health advocate's view was 'Kat should have what she wants, I'm speaking up for her this is what she wants, so this is what she should have. I'm not here for her best interests.'... Well I said 'no, I understand where you're coming from but I don't agree with you,' (Natalie, carer)

Service users' experiences of not <u>feeling heard</u> or believed however, could be seen to be influenced by their feelings of being excluded from the communication between carers and staff:

"I was lucky that I had the sort of rapport with staff where we could talk things over [but] I think sometimes Kat would say 'you're taking their side'" (Natalie, carer)

"I went to see Alan [following an incident] and he said 'My sister said blah blah blah blah,' and I said 'she didn't say that at all.' He said 'what do you mean?' [I said] 'I've just been talking to her on the phone ... I keep saying to Alan 'you keep forgetting your sister doesn't say these things, I talk to her'" (Roger, staff member)

3.4.3.2 Sub-Category: Decision Making

Service users' desires to be involved in decisions about their care were described by participants:

"[Alan told me] 'I want to come off section.' [I said] 'Do you think you're ready; Do you think you could cope with it?' [He said] 'Yes I think I do.' He said the same to staff. He still thinks a little bit that [the decision] is in other peoples' hands but he likes to have input, he likes to have his opinion known." (Sandra, carer)

In particular, accounts were described of service users voicing their opinions and being involved in decisions about their discharge plans:

"Mel is very clear about what she wants when she's discharged ... she's been involved, she's had meetings and the social worker keeps her informed." (Emily, carer)

"We all went to visit [Kat's new home] and I've got to say the first day we went the parts that they'd shown us was that the bedroom was like, for want of a better word, a hole under the stairs. It wasn't a huge bedroom but there was a living room part to it. And Kat said 'I'm not living here, look it's like a prison' ... And then 'I don't wanna live in a house with people I can't stand. I don't wanna live with these people.'" (Natalie, carer)

"My sister wants me to go into them [respite adult learning] places and I say 'no I don't wanna go into them type of places, I wanna go into another home.'" (Alan, service user)

However, service users indicated they did not always feel their opinion was listened to:

"Staff are not really listening coz if they were I would have had what I wanted." (Kat, service user)

"The Doctor has brought it up in the ward round once about going to [name of facility] and I said 'I don't wanna go all the way up that way.' And some of the staff said 'you'll like it, you'll get on with some of the people there' they said, you know." (Alan, service user)

3.5 Core Concept: Creating Safety and Protection

This core concept incorporates views about service users' vulnerability and the resultant need for inpatient units to implement strategies designed to ensure service users' safety and protection. This process is understood in relation to three categories: **vulnerability and need for protection, ensuring service users' safety** and **feeling safe.**

Figure 3.5: Diagrammatic Summary of Core Concept **CREATING SAFETY AND PROTECTION**

3.5.1 Category: Vulnerability and Need for Protection

Vulnerability and need for protection captures the view that service users were seen as having been vulnerable prior to admission and that statutory services had failed to adequately ensure their protection:

"Mel's very vulnerable, she's always been vulnerable out in the community" (Emily, carer)

"[Social services] are not very nice. They didn't do anything for me and my partner ... [My social worker] told my mother to 'back off' and that they'd do the work ... since that happened the druggies came and my partner died and I came in here. Had a POVA meeting and they said it's not safe for me and my partner to go back to the house. Two days later my social worker said 'either go and live in a B&B separate from each other or go back to the house with you seeing each other'. We wanted to be together so we went back to the house and then all [the trouble] started." (Kat, service user)

"Mel talks so normal, if you were outside you wouldn't realise she had a learning disability at all, you wouldn't, and that makes her vulnerable, very vulnerable." (Joanne, staff member)

In addition, service users' experiences of **vulnerability and need for protection** were seen to continue during their admission with accounts of violence and inappropriate sexualised behaviour from other service users:

"[Another service user] used to go for me ... he give me this bruise on the arm, you know. It happened on a Friday, I don't know what date, but it happened on Friday, he keeped hitting, he keeps hitting his fists, attacking you, you know ... Well, I don't like it you know, I don't like it anybody attacking me like," (Alan, service user)

"There was one patient there that started hitting out at Mel for reasons, well he has his problems as well, and he physically hit Mel ... And that happened a couple of times." (Emily, carer)

"[I watch TV] in the lounge with screaming people, or in the small TV lounge where people like Daniel (other service user) come in and wank themselves off in front of you ... Disgusting. I told him to get out. He won't listen so I kicked him out" (Kat, service user)

This quote from a staff member reflected the beliefs of one service user regarding the need to rely on staff to keep her safe:

"As soon as Mel had been targeted [by another service user] ... she had this overwhelming need to be friends with the staff, because she felt that she needed to at the time then, because she needed to be safe." (Joanne, staff member)

3.5.2 Category: Ensuring Service Users' Safety

This category comprises a number of ways in which services created a safe context in response to service users' need for protection. In the first instance, admission and being

sectioned were identified as means of reducing the risks to service users and others within the community:

> *"[The police] said because they could see Kat's situation and how vulnerable she was and how she was really really with the wrong people. They made sure she was charged with something so she would have to go to court and she would have to be kept away from all these people."* (Natalie, carer)

> *"I mean in the past I'll say Alan wanted to stay on section because he feels safer, he feels that the opportunity is not there for him [to abscond] so he doesn't risk anything."* (Sandra, carer)

Further interventions including restraint and close monitoring, were reported to be used during admission in order to keep service users safe in response to the potential risk to themselves or from others:

> *"Kat was threatening to harm herself at the time. So I understood that measures were put into place like staff had to visit her room every so often to make sure she was ok and safe. Things had to be locked away ... The staff had to go in and out of her room more, obviously for her safety and for their safety."* (Natalie, carer)

> *"When Mel first went there she saw it as very intimidating that they were there when she was bathing, but it was only for her safety and hygiene"* (Emily, carer)

> *"Yesterday morning we restrained Mel to be honest, because she was much angrier than I've ever seen her yesterday morning. She was aggressive, slapping and going round and hitting everyone. So the thing is, for her own safety, rather than have all the patients hitting her back, it was easier to sit her down in a seated restrain just to keep her calm, talk to her, I felt."* (Joanne, staff member)

Although service users recognised the need for these measures as a means of ensuring theirs and others safety, they held negative views of their experiences:

> *"(Participant): Staff shout at me and restrain me [when I scream, shout and try to hurt people] ... Then when people hold me to restrain me I go even more mad coz it's like they're fighting with me so I fight with them to get them off me ...*
> *(Researcher): So why do you think they need to hold you?*
> *(Participant): Safety.*
> *(Researcher): Whose safety? Yours or theirs?*
> *(Participant): Both"* (Kat, service user)

> *"I was restrained and I didn't like that ...For my safety. To keep me safe from escaping again."* (Mel, service user)

3.5.3 Category: Feeling Safe

Despite service users' ongoing experiences of vulnerability on the unit and their negative reports of strategies employed to ensure their safety, this category represents the positive perceptions that some service users did feel safe on the unit:

"Well, I feel safe here I do. I feel safe in this place I do." (Alan, service user)

"I think Mel feels safe here and I think she likes the fact that she's got boundaries and people are being professional with her, I think she does like it ... I don't think Mel's particularly in a hurry to go to be honest, she feels safe here, she does like the staff, you can tell, this is the happiest I've seen her in a long time." (Joanne, staff member)

3.6 Core Concept: Understanding and Meaning

This concept refers to how **UNDERSTANDING AND MEANING** was constructed and shared between service users, carers, staff and other professionals. This concept incorporates three categories: **sharing understanding, understanding the service user** and **making sense of change**.

Figure 3.6: Diagrammatic Summary of Core Concept **UNDERSTANDING AND MEANING**
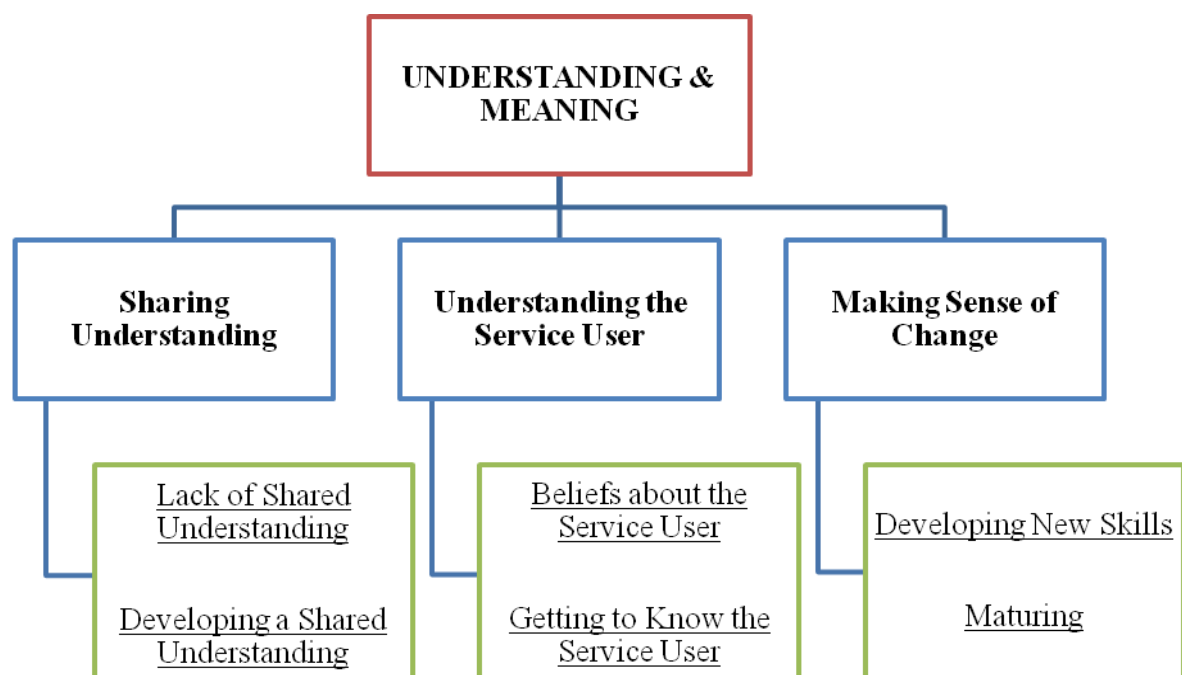
3.6.1 Category: Sharing Understanding

Carers and staff described a <u>lack of shared understanding</u> that often existed between themselves and service users and the strategies that were employed with the aim of <u>developing a shared understanding</u>.

3.6.1.1 Sub-Category: Lack of Shared Understanding

Service users' understanding of the process of their admission, and the events which occurred during it, were perceived by carers and staff to be limited by difficulties service users had in being able to make sense of the situations they encountered:

> *"Alan couldn't understand [the way another service user behaved] and I didn't know how to explain to him that [the other service user] can't help their behaviour."* (Roger, staff member)

> *"Kat couldn't understand that was a dangerous thing that she did and that you've got to have consequences."* (Lucy, staff member)

> *"I don't think Mel would understand about sections and things. All she knows is she's in here because we've got to keep her safe, we've got to keep the environment safe ... she knows all of that, but she doesn't understand the big picture of where she's going to go and things like that."* (Joanne, staff member)

Carers and staff also reflected that service users did make sense of situations, however they often did this in a way which suggested that they held a different perception or interpretation of the situation to carers and staff:

> *"The most difficult thing I think they had to deal with was Kat not understanding things and her misinterpretation of the way things are said to her."* (Natalie, carer)

> *"If someone has said something and Alan has thought it to be a bit harsh, maybe if somebody has said 'hang on a minute,' Alan would [interpret] that as 'shut up.'"* (Roger, staff member)

> *"[Staff] say that Mel misinterprets things."* (Emily, carer)

The negative impact of service users 'misinterpreting' things that were said to them was illustrated by the following quote:

"Staff would say something in a jokey way. Whereas if you or I were given something now and we were friends, I would say 'you were spoilt having that.' Kat would take that as a real criticism and would misinterpret the fact that it was meant in a jokey fashion as 'oh, you're spoilt' [jokey tone of voice]. She would take it as 'you're spoilt you are' [harsh tone of voice]. Everything was the negative way ... Everything was taken personally." (Natalie, carer)

Sometimes, misinterpretations were thought to be intentional and possibly a way of service users' asserting some control and influence over situations:

"Where staff have said 'get on with it or go to your room' Alan would say 'they called me this, they said this, they pushed me.' He will embellish and it will be purely to get his own back on this member of staff." (Sandra, carer)

3.6.1.2 Sub-Category: Developing a Shared Understanding

It was acknowledged by carers and staff that service users wanted to understand what was happening during their admission and needed to be given explanations:

"People saying no to him ... Alan sees it as 'why? Give me an explanation.'" (Sandra, carer)

"Mel needs an answer when it's going to happen, she needs a date and a day.'" (Joanne, staff member)

In order to ascertain how service users had interpreted things that were said to them and to ensure they shared carer's and staff's understanding of a situation, a number of strategies were employed. Examples of carers and staff clarifying what service users had understood and providing explanations were described:

"I always say to Alan 'now what did I say to you?' [He says] 'I don't know.' [I follow it up with] 'What do you think I said to you?' to see what he thinks I said which I think is more important than him understanding exactly what I said. It's more important for me to know what he thinks I said because he might get the wrong end of the stick ... [if he doesn't understand] I'll try to explain it another way.' (Roger, staff member)

"You have to sit with Kat and say 'what do you understand, what do you think that means?' [The unit manager] has a brilliant way of doing it, talking to her about something then saying 'now tell me what you think I've just said to you, which way you think I meant it'." (Natalie, carer)

A culture of working together as a team and providing consistency in explanations and responses was also recognised as a means of promoting service users' understanding:

"On the ward you have to, as a staff team, be working together all the time ... you make sure before you answer you already know that Mel hasn't asked everybody else ... I'll always find out if Mel's asked people before, because that's the way to work positively with her. And I'll say, 'you've already asked staff and you have been told your washing is this afternoon.' I've said, 'I can't put your washing with you now because you'll be taking other service users' time and it's this morning.'" (Joanne, staff member)

"But all the staff worked hard and we all sort of supported Kat and we all said the same thing we all supported her the same." (Lucy, staff member)

3.6.2 Category: Understanding the Service User

This category is concerned with carers' and staff's <u>beliefs about service users</u> and the process of <u>getting to know the service user.</u>

3.6.2.1 Sub-Category: Beliefs about Service Users

Carers and staff described the impact of developing <u>beliefs about service users</u> based upon how they appeared and the negative consequences this could have in relation to people having unrealistic expectations of them:

"I don't think [her previous support staff] knew the real Mel. A lot of people take her at face value because she looks normal, and at the end of the day she has got a lot of problems." (Emily, carer)

"Mel's a very good at communicating and she seems very able, but really her social skills are quite poor, and I think that's the most problem for her because people, their expectations of her are too high ... I think sometimes the amount that she can take on board I think is not as much as people think, like I said, the expectations." (Joanne, staff member)

"Because Alan talks so well, people will say 'you say to him, he knows, it's over.' But he doesn't always." (Roger, staff member)

Carer's and staff's <u>beliefs about service users</u> being demanding and complex were also highlighted:

"Alan is 'I want, I want, I want' and this has always been his life." (Roger, staff member)

"Kat's very draining ... She's very difficult to work with, she pushes people to the limit, really to the limit and I think some of the staff found her very difficult to work with and I fully understand that having had her for 26 years with me." (Natalie, carer)

"The patients that we have in here are particularly complex ... Mel's been in and out of different placements over the years, and she is really a complex person ... I would say that she's been very, very demanding, whatever anybody else is doing, she's got to have the same ... they're all intense ... but she is the most intense with it." (Joanne, staff member)

A narrative that was presented for all service users related to carers' and staff's perceptions of service users also being manipulative, telling lies and making allegations:

"Alan will make up stories as well that staff have said things or done things, and we are aware that he does embellish ... but we have to investigate any allegations made, the same way that staff have to be investigated." (Sandra, carer)

"Kat made a lot of allegations against the staff which we knew weren't right." (Natalie, carer)

"I think Mel cries wolf a lot." (Joanne, staff member)

The <u>beliefs about service users</u> that carers and staff held can be seen from the quotes below to have impacted upon how staff approached the task of supporting them, as well as affecting their discharge plans:

"And because Alan's [made allegations] in the past and they've been false allegations, I said, 'don't you understand people are less likely to believe you now because you've told lies in the past? You're just making things worse for yourself. The more incidents, the less likely people will take you. They will look at your file and say, 'well we don't really want him, he's a bit of a troublemaker, he can do this,' we can't take that risk. So it's less likely of you getting a place to move on to.''" (Sandra, carer)

"You'd be a bit wary going in Kat's bedroom because then the next minute she might be saying things like 'so and so, so and so called me names when I was in the bedroom on my own with her,' and get them into trouble." (Lucy, staff member)

"Mel's always making allegations, and you've got to realise she's been on various placements and this same pattern of this was happening, and it's in her notes that she makes allegations." (Joanne, staff member)

For service users the effect of carers and staff holding these beliefs about them being demanding, complex, manipulative and lying, sometimes resulted in the experience of not feeling believed and becoming distressed:

"[I told] some of the staff [that a staff member was winding me up] and they say 'no I don't think she'd do that' … they believe her over me … coz she said before 'do you honestly think they'd believe you over me?'" (Kat, service user)

"There are situations where I will say to Alan that I don't think it's true, 'Is this true?' And he'll say, 'honestly, honestly,' and I'll think, 'It's not true.' And I will ask him a couple of times and then I know I've got to stop because he's is getting upset by me asking him." (Sandra, carer)

3.6.2.2 Sub-Category: Getting to Know the Service User

This sub-category incorporates participants' views regarding the importance of understanding and getting to know the service user in order to provide appropriate care and support:

"The social worker had the tools to section Kat before any of this happened and didn't because she thought she was just a spoilt little madam because she hadn't taken the time to get to know her … You know, it's all about people's understanding and people taking time out to sit back and think." (Natalie, carer)

The effectiveness of the assessment and treatment units in getting to know the service user and in sharing their understanding with carers is illustrated in the following quotes:

"I think staff are beginning to understand Mel now, like I said, from when she first went there. When she first went there she was quite angry and things like that, and they just sort of took her at face value and they didn't really know her … they seem to understand her a bit better now." (Emily, carer)

"To me that would be my biggest positive out of it that they've taken the time to get to know Kat and accept her for what she is and learn strategies to deal with her which nobody has ever done before" (Natalie, carer)

"I'll miss the staff because they know me very well." (Mel, service user)

"The staff know Alan inside out. They will ring me and say, 'have you noticed Alan's a bit off, he's looking elsewhere, he's becoming edgy.' If you were taking him out they'd say, 'be aware of this.' They are absolutely spot on, you know." (Sandra, carer)

3.6.3 Category: Making Sense of Change

This category relates to how participants viewed recovery and made sense of the changes in service users' presentations during the admission. Two processes of change were constructed: developing new skills and maturing.

3.6.3.1 Sub-Category: Developing New Skills

Change was understood in relation to service users having learnt new daily living skills, such as making the bed and budgeting, and having improved communication skills:

> *"I didn't used to be good at making the single bed but I'm great at it now."* (Mel, service user)

> *"'£30 will be alright' Alan said 'coz I'll have some change from this.' So he's learnt that now, you know. So we went back out drew £30 out of the till, we got the shirts, got everything else he wanted and he still had change back for his tin for the week. But it's taken a while."* (Roger, staff member)

> *"For the first time ever Kat's rung me and said 'how are you mum?' That's a major step. Like before it would have been all her, totally her and then might have asked something at the end."* (Natalie, carer)

Change was also recognised in service users' abilities concerning their own <u>behavioural and emotional management</u>:

> *"[Alan knows he's getting better] because of his self checking. [He'll say] 'another day and I haven't misbehaved' and even to the point where when he has had, as he calls it, a blip and you go into his calendar and he'll put a cross on it."* (Roger, staff member)

> *"I used to go mad. Swear, shout, scream, throw things. I have once hit the staff. But I haven't done that for 7 weeks now."* (Kat, service user)

> *"Mel's learning to deal with her anger better. She'll go down her room, before she'd be slamming all the doors and I'd say, 'If you don't feel right, go down your room and have time out on your own. Put the radio on or put a DVD on, there's lots of things you can do, or talk about it,' and she tends to do that."* (Joanne, staff member)

3.6.3.2 Sub-Category: Maturing

A process of <u>maturing</u> is presented as another means of **making sense of change** that occured during admission:

> *"I think Alan sees it as he's grown up a bit … I think he thinks, 'I'm growing up now, I'm more of an adult.'"* (Sandra, carer)

> *"I think Kat's matured since she's been in the assessment and treatment unit. They've done a lot with her but it's hard to put your finger on what it is but she's definitely matured in some way."* (Natalie, carer)

"It's good to come off section. You can prove to staff that you can do more and be trusted ... be good, kind of wise." (Alan, service user)

However, carers reflected that they felt some aspects of service users' difficulties and behaviours were unlikely to change:

"I think that [Kat's rage] is part of her makeup ... [it's] gonna stay the same, that's her makeup, her personality." (Natalie, carer)

"I think that's just Mel and she's always going to be like that, she's always going to have these problems." (Emily, carer)

3.7 Making Sense of the Experience: A Grounded Theory

The model in figure 3.7 represents a grounded theory of the interacting factors that participants' responses suggested may influence how adults with a learning disability experience admission in specialist inpatient assessment and treatment units.

The model proposes that the psychological processes represented within the concepts of **SENSE OF SELF AND CONNECTEDNESS, SENSE OF AGENCY** and **CREATING SAFETY AND PROTECTION** are significant for service users in making sense of their experience. For example, how closely service users related to the idea of having a learning disability; the quality of their relationships with others; their perception of being on section; and feelings of both vulnerability and safety upon the unit can all be seen to influence how they made sense of and experienced their admission. Furthermore, the model proposes that these factors contribute towards how **UNDERSTANDING AND MEANING** around the admission is constructed and shared between service users, carers and staff. The model goes on to suggest that service user's experiences are influenced not only by what happens to them, as represented within the procedural aspects of the **COURSE OF ADMISSION**, but also by how they make sense of their experience of admission and the **UNDERSTANDING AND MEANING** that is constructed and shared.

It is important to note that the proposed model is based upon the researcher's interpretations of the data and it is therefore recommended that the model is further explored and tested, as discussed in section 4.6.

Figure 3.7: Grounded Theory Model

SENSE OF AGENCY

- **Autonomy & Freedom**

- **Externally Imposed Constraints**

- **Service User Inclusion & Involvement**

SENSE OF SELF & CONNECTEDNESS

- **Identification with Learning Disability**

- **Relationships with Staff**

- **Relationships with Family**

- **Valued & Meaningful Sense of Purpose**

CREATING SAFETY & PROTECTION

- **Vulnerability & Need for Protection**

- **Ensuring Service Users' Safety**

- **Feeling Safe**

UNDERSTANDING & MEANING

- **Sharing Understanding**

- **Understanding the Service User**

- **Making Sense of Change**

THE COURSE OF ADMISSION

- **Being Admitted**   - **Assessment & Treatment**   - **The Discharge Process**

CHAPTER 4: DISCUSSION

4.1 Chapter Overview

The aim of the current study was to examine the experiences of adults with a learning disability in specialist inpatient units, drawing upon the perspectives of service users, carers and staff. This chapter provides a summary of the key findings from the current study which are reviewed in relation to the existing literature. The contribution of the research to the current understanding of service users' experiences of specialist inpatient units and how this might be understood from a theoretical perspective is outlined. The clinical implications of the results are discussed and a critical appraisal of the methodological strengths and limitations of the research presented. Finally, recommendations for future research are considered and the conclusions of the study are summarised.

4.2 Summary of the Research Findings and Review in Relation to Existing Literature

4.2.1 The Course of Admission

Three key factors seem to be important in the course of admission, namely being admitted; assessment and treatment; and the discharge process. In relation to the process of being admitted, and similar to findings reported by Chinn *et al*. (2011), some service users viewed admission as punishment and units as being like a 'prison'; whilst others viewed the unit as a place of safety, respite or transition in line with findings from Donner *et al*. (2010). Furthermore, admission appeared to serve an important function in the assessment and treatment of service users' physical health which may indicate ongoing health inequalities and poor community access to healthcare contrary to the Department of Health's (2009) agenda. It is interesting to note that these functions do not reflect the desired purpose of the unit as an acute facility designed to address exceptional challenging behaviour or mental health difficulties. Service users' differing views around their reason for admission and the purpose of the unit appeared to reflect, in part, their previous experiences and different routes to admission. For some service users the process of admission was experienced as traumatic and, similar to findings from Parkes *et al.* (2007), service users reported feeling angry, anxious and scared. In response to this, the current

findings highlight that familiarity with the unit from previous admission and the presence of an induction and orientation period contributed positively to service users' experiences of admission by supporting them in understanding what was happening and thereby reducing anxiety.

What happened to service users in terms of the assessment and treatment they received whilst on the unit was also significant. Engagement in activities, in particular going out from the unit, appeared to be a pertinent aspect of service users' positive experiences of admission. In support of findings from previous studies service users appeared to particularly value those activities which promoted independence, choice and control (Scior & Longo, 2005; O'Brien & Rose, 2010). However, difficulties in providing predictability and routine in relation to activities off the unit were described which often resulted in disappointment and frustration for service users, as previously described by Scior and Longo (2005) and Parkes *et al.* (2007). This may be attributed to limited staffing capacity or availability, as well as reflecting inherent difficulties for acute inpatient units which by their nature are unpredictable environments designed and resourced to provide therapeutic rather than social activities for service users (Hoefkens & Allen, 1990).

The assessment and treatment units involved in this study all employed a Positive Behaviour Support (PBS) approach to understanding and managing service users' challenging behaviour (see section 2.8.3). Consonant with this approach, and previous findings from Chinn *et al.* (2011), participants valued 'talk time', which may be regarded a proactive approach to behavioural and emotional management, and saw this as providing them with comfort and help to manage their challenging behaviour. Furthermore, the use of medication as a strategy for behavioural and emotional management received mixed views. As reported by Scior and Longo (2005), some carers in the current study felt that service users were overmedicated and its effectiveness was questioned. However, in contrast to the conclusions of Chinn *et al.* (2011) and Parkes *et al.* (2007), service users in the current study did not report feeling concerned about medication or feeling forced into taking it. It is interesting to note that although therapeutic input from other professionals was described by participants, this was not a focus of their accounts. The reasons for this are unclear but may be a reflection of service users not experiencing talking therapies as therapeutic per se or due to a limited availability of psychotherapy as reported in previous research (Chinn *et al.*, 2011; Parkes *et al.*, 2007).

A number of issues relating to the discharge process were also highlighted. Assessment and treatment units are designed to provide short term admission. However, the current study supports conclusions from previous research which highlights that service users may be at risk of extended periods of admission, on occasion resulting in 'bed blocking', due to a lack of appropriate community services (Chaplin, 2004; Hall *et al.*, 2006; Pitt, 2011; Slevin *et al.*, 2008; Watts *et al.*, 2000). A number of negative implications related to this were identified in the current study including service users becoming 'too comfortable' on the unit and a risk of becoming 'institutionalised'. However, it is important to note that service users did not report negative views of being on the unit for extended periods of time, as might be expected, instead describing not wanting to leave the unit. This may be due to a number of reasons, some of which are discussed below.

4.2.2 Sense of Self and Connectedness

Service users' views of themselves and their relationships with those around them, including staff; carers and other service users, were influential factors in how they experienced admission. In support of findings from McNally *et al.* (2007) and Scior and Longo (2005), the current study reports that service users had difficulties in relating to other service users thereby isolating themselves on occasion. In comparison to others whose disabilities they judged negatively, service users viewed themselves as 'normal' and 'capable'. Indeed, McKenzie (2011) proposed that adults with a learning disability need varying degrees of support and therefore may not be appropriately placed together in specialist services, a view that was held by some carers in the current study. Bringing together service users with different levels of disability, need and at different stages of acute illness was reported to result in service users engaging in or copying the challenging behaviours of others. However, opportunities to adopt a role as carer to other service users or as a helper to staff appeared to provide a valued and meaningful sense of purpose for service users which contributed positively to their experiences, possibly as a consequence of increasing their self-esteem and well-being (Blunden & Allen, 1987; Chinn *et al.*, 2011).

In contrast to the lack of connectedness service users felt with other service users, they largely experienced positive relationships with staff. Similarly, Clarkson *et al.* (2009) found that in forensic settings service users viewed staff as having a parental role, whilst Scior and Longo (2005) also highlighted the importance and significance of service users'

relationships with staff. Furthermore, in support of findings from McNally *et al*. (2007) it may be concluded that service users aligned themselves more with staff than other service users, which contributed towards a greater sense of connectedness and created a '*sense of belonging*' (pp.50). However, consistent with findings from Chinn *et al*. (2011), one service user did indicate negative interactions with staff which appeared to increase her feelings of isolation on occasion.

Relationships with family were also significant for service users during their admission. The traumatic experience of being admitted to the assessment and treatment unit may in part be attributed to service users' experiences of being separated from their families which some experienced as a rejection. Consistent with findings presented by Chinn *et al*. (2011) and McNally *et al*. (2007), being separated from family was found to contribute to service users' feelings of distress and loneliness. Maintaining and increasing contact were therefore found to be important for both service users and carers, particularly where significant family events took place. In addition, service users indicated that they would like to return home or at least remain close to family upon discharge, suggesting service users had maintained a strong relationship with family members during admission.

4.2.3 Sense of Agency

Factors affecting service users' sense of responsibility and control over what happened during their admission and feelings of involvement and inclusion were also highlighted throughout participants' narratives. Service users talked about how life on the assessment and treatment unit compared to their life in the community with regards to the level of autonomy and freedom they experienced. Negative views expressed were associated with a loss of control and independence, the restrictive experience for service users of having staff accompanying them to go out and being on section. McNally *et al*. (2007) also found that the experience of being sectioned was associated with feelings of powerlessness. Restrictions on service users' actions were also described as a result of unit boundaries and rules, which service users largely viewed negatively. Feelings of disempowerment created by the enforcement of rigid rules have also been described in previous literature (Donner *et al*, 2010).

In particular, restrictions around access to money were highlighted in the current study as a result of both unit rules and requirements to 'negotiate' this with staff. Although staff described making decisions with service users' 'best interests' in mind, it would appear that this was not always how it was experienced by service users themselves. Rather, this was described by service users as staff trying to be in control of their lives and telling them what to do. In line with findings from Jacques & Stranks (2009) service users indicated that they wanted their views, opinions and wishes in relation to the care they received to be heard, however they also reported not always feeling involved or included. Indeed, similar to findings from Donner *et al*. (2010, pp.219) who reported service users having to '*fight with*' staff to be heard, participants indicated that service users often had to shout, go mad or be persistent in their requests in order to feel heard. However, in relation to decisions about discharge, service users were described as being able to express their opinions and be included in this decision making process, although some indicated that this experience did not always equate to feeling heard. It may be suggested that service users' perceptions of staff as having control and authority may have limited their experience of feeling heard and being involved in decision making, as proposed by Parkes *et al*. (2007).

With regards to supporting service users' inclusion and involvement, the importance of advocacy has been extensively highlighted in previous research (Bonell *et al*., 2011; Hoole & Morgan, 2011; Samuels *et al*., 2007). Consistent with this, carers in the current study described their experiences of advocating for service users to ensure things were done in their 'best interests', viewing their advocacy role as important and beneficial to ensuring service users' well-being. However, service users' experiences of this were not clear and it was apparent that the experience of carers and staff communicating and making decisions with each other may sometimes have resulted in service users feeling excluded.

4.2.4 Creating Safety and Protection

Participants described a number of issues regarding service users' vulnerabilities and need for protection and those strategies employed to ensure their safety. Concerns regarding service users' safety in inpatient units have been highlighted in previous research (Donner *et al*., 2010; Parkes *et al*., 2007; Scior & Longo, 2005) and are further raised within the current study. Murphy *et al*. (2007) proposed that incidents of assault and violence left service users feeling threatened, in need of protection from staff and elicited feelings of

vulnerability. It is therefore possible that the incidents of assault and inappropriate sexualised behaviour directed by other service users, described in the current study, contributed to the difficulties in the relationships between service users. However, in contrast to evidence that service users' experienced staff as unfriendly and uncaring when looked to for protection (Scior & Longo, 2005), the positive relationships that service users in the current study had with staff may be considered a protective factor in service users feeling safe.

A number of specific procedures and strategies employed to ensure service users safety were also highlighted in the results and may be seen to contribute to service users overall feelings of safety on the unit, as reported by participants. In particular, staff described the use of restraint, in line with the positive behavioural support approach, as a last resort in responding to challenging behaviour. Whilst service users described the experience of being restrained negatively, they also talked about how they understood this to be necessary at times in order to ensure their own and others' safety, as previously described by Hawkins *et al*. (2005).

It is interesting to note that in contrast to previous studies (Donner *et al.,* 2010; Samuels *et al.,* 2007), issues relating to the overall unit environment, for example being intimidating, frightening, drab and gloomy, did not feature in participants' accounts. This may reflect the fact that the units had been specially designed to withstand the effects of challenging behaviour (Blunden & Allen, 1987) and that service users and carers were largely satisfied with the environment, as found in previous studies of specialist inpatient services (Scior & Longo, 2005).

4.2.5 Understanding and Meaning

The way in which understanding and meaning was constructed and shared between service users, carers and staff is identified as a significant factor in service users' experiences of admission. In relation to developing a shared understanding, staff and carers emphasised throughout their accounts that service users' experiences and understandings of situations did not always match those held by themselves. Although the findings discussed above indicate that service users were able to make sense of many aspects of their admission, they did so from their own perspective which staff and carers often viewed as service users

not understanding or misinterpreting the situation, rather than having a different but valid perspective.

Understanding what was happening during their admission, however, was identified as important for service users, and staff described their provision of explanations and consistency of responses to facilitate a shared understanding with service users. However, as indicated in section 4.2.3, service users did not always feel that their views or opinions were heard and thus a truly shared understanding may have been difficult to achieve, a finding also reported in relation to service users' experiences of general healthcare (Gibbs *et al.*, 2008).

Service users' experiences of admission were also found to be influenced by other people's beliefs about them, including beliefs about them being demanding, manipulative and lying, which appeared to affect interactions and service users' experiences of feeling heard and being believed. The importance of getting to know service users and developing a shared understanding in order to better support them and appropriately meet their needs was therefore emphasised and recognised as a strength of the unit. This finding supports the view that staff in specialist inpatient units may have the skills and expertise to understand and support service users with complex needs (McKenzie, 2011).

In contrast to findings from the previous literature reviewed, service users' recovery and the process of change was understood in relation to a number of factors not solely in terms of improvements in behaviour (Murphy *et al.,* 1996) and compliance with medication (Donner *et al.,* 2010). Participants described a process of maturing as service users were trusted with jobs which provided a sense of purpose and displayed positive improvements in terms of their behavioural and emotional management, a findings supported by Murphy *et al.* (1996). The view was also shared across participants that service users had developed new skills during their admission. However, a therapeutic pessimism also existed amongst carers who felt that some aspects of service users' difficulties were unlikely to ever change.

4.3 Theoretical Discussion

The findings from the current study suggest that it is important to consider how interactions, relationships and patterns of behaviour between service users, carers, staff and other service users influence the construction of meaning, understanding and experience within the context of the inpatient unit.

Drawing upon a systemic framework the findings suggest that service users make sense of their experiences within the context of relationships, patterns of behaviour and interactions with others (Baum, 2006; Freedman, 2001; Vetere & Dallos, 2003). Indeed, many different systems and relationships, including those with staff, carers and other service users; the identification with the concept of having a learning disability; and the impact of wider community service provisions can be seen to have contributed to service users' experiences. This would appear to support the view that service users are part of of multiple systems which influence their experiences and therefore support the application and consideration of systemic thinking to understanding their experiences (Lynggaard *et al*., 2001; Baum, 2006, 2007). Accordingly, the grounded theory model presented indicates that the three relational concepts of 'sense of agency'; 'sense of self and connectedness'; and 'creating safety and protection' represent important factors in how service users make sense of their experience within the context of the service environment, culture or their relationships with others. For example, in line with previous findings and the systemic approach, service users' experiences of control may be seen to be connected to relationships with staff (Donner *et al.*, 2010); their feelings of vulnerability linked with interactions with other service users (Chinn *et al.,* 2011) and separation from family related to feelings of loneliness (Chinn *et al.,* 2011).

The model thus suggests that these relational concepts may influence how the procedural aspects of admission are experienced through their contribution to the construction of understanding and meaning. Indeed previous research has identified that the meaning service users attribute to the reason for admission or purpose of restraint for example, influences how admission is experienced (Donner *et al.,* 2010; Scior & Longo, 2005; Parkes *et al.,* 2007). Applying a social constructionist approach, the model presented proposes that the construction of understanding and meaning is influenced by service users' views of themselves, their identity, their relationships and experiences, as well as by

the beliefs held about service users by others (Freedman, 2001; Pearce, 2004). It is therefore suggested that the experience of admission is influenced by a co-construction of understanding and meaning between service users, staff and carers. It is of note that this idea has received little discussion in the previous literature reviewed, yet is highlighted as a significant component of the model presented here.

The importance of service users' relationships with staff and carers and their need for safety and protection may also be understood from an attachment perspective. Service users described the trauma of being separated from their family and the importance of maintaining contact with them during admission. This may reflect the enduring nature of the attachment bonds which characterise these relationships (Bowlby, 1969,1973,1980). Furthermore, as proposed by Lynggaard (2005), the current study found that service users described their relationships with staff as being particularly important with regards to meeting their physical needs, providing comfort and promoting feelings of safety. Thus, the relational bonds that service users experienced with staff may be conceptualised as attachment bonds similar to those experienced with family members.

The implications of considering service users' experiences within attachment, social constructionist and systemic frameworks are described further in the next section.

4.4 Clinical and Service Development Implications

The current study identified a number of factors that influenced service users' experiences of specialist inpatient admission, which indicate several possible clinical and service development implications. Recommendations for staff and carers supporting people with a learning disability in specialist inpatient units, as well as for the development of inpatient and community service provision, are discussed below within the context of the research findings, previous literature and theoretical considerations.

4.4.1 Developing and Sharing Understanding

Overall, participants reflected that developing a better understanding of service users as well as promoting service users' understanding, were positive outcomes of admission that provide important focuses for clinical practice.

It was found that service users wanted to know what was happening with regards to their care and why, with findings highlighting the importance and impact of this upon how service users experienced admission. It is therefore important that service users are supported to develop an understanding of experiences during their admission with information about them being made accessible, a recommendation that is supported by Scior & Longo (2005). Indeed, it is argued that providing accessible documentation for service users using pictures, symbols and easy read text, should be a key priority for services in order to promote equality and inclusion of people with a learning disability (CHANGE, n.d).

The current study also highlighted a number of verbal strategies that staff and carers implemented to communicate information with service users in order to try to create a shared understanding with them. Strategies that staff reported as being helpful included providing explanations, ensuring they were consistent in their responses to service users and clarifying with service users their understanding of what had been said. This may be seen to highlight the need for staff to ensure that giving information is balanced with listening to and hearing how service users have understood this. The research suggested that service users' understandings of situations were often viewed by staff as misinterpretations, however it is argued that service users' understandings are no less accurate than staff's but simply reflect meanings constructed from different perspectives (Baum, 2006; Vetere & Dallos, 2003). Therefore, in order to better facilitate the development of shared understandings, mechanisms need to be put in place to support staff in understanding how service users view themselves and the perspective from which they might construct meaning. Indeed McNally *et al.* (2007) also emphasised the need for staff in inpatient services to be aware of service users' feelings, particularly those related to vulnerability and powerlessness, in order to understand their experiences and better support them.

Using a systemic approach, service users and individuals within their support network may be brought together to collaboratively construct shared understandings of service users' experiences by exploring the multiple perspectives and understandings that exist (Lynggaard *et al.,* 2001). Network training sessions, for example, offer a systemic framework through which this can be achieved using systemic principles to consider the relationships, beliefs, actions, communication patterns, and wider contextual factors that

influence service users' experiences (Jenkins & Parry, 2006). Involving service users may also contribute towards enhancing their feelings of being heard and promoting the view that all perspectives are valid and useful in constructing meaning and understanding.

The provision of ongoing psychological consultation and supervision may also contribute towards helping staff to understand service users' perspectives. In addition, this would enable staff to recognise the implications of attributions and perceptions they hold about service users being manipulative or lying, for example, upon how they interpret and respond to service users' behaviours. Indeed, the necessity to provide appropriate training and support to enable staff working in inpatient settings to develop more helpful ways of understanding and responding to services users has also been highlighted by Scior & Longo (2005). This may be a role that Clinical Psychologists working within learning disability services could adopt.

4.4.2 Developing Person-Centred Support Plans

The current findings indicated that some aspects of support plans, such as access to money, were dictated by service level restrictions. The development of individualised person-centred support plans is recommended however as a means of increasing service users' choice and control (Department of Health, 2009) and reducing feelings of de-personalisation that are associated with the use of group schedules and plans (Chinn *et al.,* 2011).

In line with previous research, the findings from the current study also highlighted the tensions for services between promoting service users' control, independence, autonomy and freedom, with implementing restrictive strategies necessary to ensure their safety (Bond & Hust, 2010; McNally *et al,* 2007; O'Brien & Rose, 2010). Including service users in the development of their support plans is likely to go some way towards managing these tensions. Similarly, Hawkins *et al.* (2005) recommended that service users were supported to understand the reason for restrictions and the influence of their own behaviour upon the necessity for interventions such as restraint. In line with this suggestion, current findings indicated that although service users experienced incidents of restraint negatively, where they were able to understand the necessity of this to ensure safety, they experienced the unit overall as a safe place.

The implementation of a positive behavioural support model (Allen *et al.,* 2005) is also supported by the current study. Findings indicated that service users experienced the consistent support, regular talk time and boundaries associated with this approach as comforting and safe. Furthermore, this approach may be seen to have enabled service users to better manage their own behaviour thereby enabling them to be more independent and enhance their sense of responsibility.

4.4.3 Promoting Attachment Relationships

Findings from the current study highlighted that service users valued their relationships with staff, at times describing these as being comparable to family relationships. Therefore, findings would seem to suggest that staff have an important role in offering service users social and emotional support within the context of relationships that could be viewed as attachment relationships (Lynggaard, 2005). The absence of positive attachment relationships for adults with a learning disability has been linked with an increased risk of challenging behaviour therefore it would appear to be important that these relationships are nurtured during inpatient admission (Allen, 2008; Allen & Davies, 2007).

A number of ways in which staff can provide social and emotional support have already been highlighted within the research findings, for example providing talk time, taking time to understand the service user and providing clear and consistent boundaries. However, Lynggaard (2005) reports that staff may not recognise their role and value in service users' lives which may cause them difficulty in responding appropriately to service users' social and emotional needs, and attachment behaviours. Staff may therefore benefit from further training and psychological consultation in order to raise awareness about attachment relationships and their contribution to the psychological experiences and well-being of people with a learning disability. This may be particularly important in relation to helping service users to prepare for and manage their feelings around discharge when relationships with staff will change again and possibly be lost. Involving service users in the discharge process and ensuring relationships can begin to be formed with new staff will also be important.

4.4.4 Maintaining Family Involvement

Attachment theory also provides a framework for considering the importance of maintaining service users' relationships with their families. Findings indicated that admission resulted in a disruption of important family relationships for service users. Therefore, in support of recommendations by Scior & Longo (2005), it is proposed that services need to support and nurture contact between families and service users in order to maintain these connections and attachment relationships. Services in the current study were recognised for their efforts in establishing open channels of communication between families and services, facilitating regular contact and ensuring service users were included in important family events. The findings also support the use of a key worker or primary nurse system in order to ensure carers have a key point of contact and continuity in their communication with services (Samuels *et al.,* 2007; Scior & Longo, 2005).

The findings from this study also support arguments for the provision of local and accessible services that facilitate ongoing contact with carers and the maintenance of family relationships (Chinn *et al.* 2011). This has implications for the future development of services with a need to ensure local inpatient provision is available to reduce the necessity for service users to be placed out of area, which not only disrupts relationships but also has significant cost implications for local authorities and health boards (Allen, 1999).

4.4.5 Improving Advocacy

The importance of maintaining relationships and communication between services, carers and service users is also recognised in relation to enabling carers to act as advocates for service users (Department of Health, 2009). Previous research has highlighted that carers acting as advocates can promote service users' sense of control, equality and inclusion (Hoole & Morgan, 2011; Murphy et al., 1996; Scior & Longo, 2005).

However, the current findings indicated that carers did not always share service users' views on situations and their advocacy was sometimes biased by their own perception of what was in the service users' best interests rather than being driven specifically by the service users' wishes. At times, the inclusion of carers was therefore felt to have resulted in

service users feeling excluded and unheard. Consequently, the inclusion of carers needs to be balanced with the active inclusion of service users in decision making processes. The Department of Health (2009) identify a number of approaches to advocacy including self-advocacy, professional advocacy and peer advocacy. None of the service users in the current study reported having accessed any form of independent advocacy support. Inpatient services may therefore enhance service users' experiences of inclusion and feeling heard by establishing links with local advocacy groups and organisations such as People First. This is also likely to contribute towards service users' inclusion in research, and service evaluation and development, in line with Government agendas (Department of Health, 2001).

4.4.6 Provision of Peer Relationships

Current and previous findings have highlighted that adults with a mild learning disability often feel different to other service users (McNally *et al.,* 2007), resulting in poor relationships between them and feelings of isolation (Scior & Longo, 2005). These experiences are reported to impair service users' self-esteem and hinder their inclusion within the unit (Blunden & Allen, 1987; Chinn *et al.,* 2011). It is therefore proposed that specialist inpatient services need to consider ways in which adults with a mild learning disability can be supported to develop or maintain relationships with peers they feel connected to in order to enhance inclusion and protect their self-esteem.

These findings may be considered to contribute towards the argument that adults with a mild learning disability are better placed in mainstream services. Scior & Longo (2005) reported that adults with a mild learning disability were able to make friends in mainstream services, which increased their experiences of integration and normalisation in comparison to those in specialist inpatient units. However, mainstream services, although providing a peer group with whom adults with a mild learning disability may feel more connected to, may not be appropriate in meeting service users' complex needs (Department of Health, 2001, 2007, 2009; Royal College of Psychiatrists, 2003). Therefore, it is proposed that better links should be established between inpatient and community services in order to support service users to develop a peer group they identify themselves with, thereby reducing risks of isolation, low self-esteem, stigmatisation and exclusion (Department of Health, 2009). The development of integrated services may also be supported by these

findings, however to ensure the effective implementation of this service model a solid foundation for inter-agency working will need to be established in response to findings from Donner *et al.* (2010).

4.4.7 Provision of Therapeutic Activities

The current study found that service users valued activities which provided them with a role and sense of purpose. Meaningful activities should therefore be provided within inpatient services which not only provide engagement but also have a therapeutic function in order to enhance self-esteem, independence, motivation and well-being (Bond & Hurst, 2010). This is also important in providing service users with opportunities to enhance their daily living skills and achieve a sense of trust and responsibility, all of which appeared to contribute positively to their experiences of change and maturing.

However, it is recognised that there are a number of barriers to increasing the provision of activity including the unpredictability of inpatient environments which disrupts activities and low staff-service user ratios which restrict the provision of necessary one to one support (Hoefkens & Allen, 1990). These difficulties again point towards a need to consider engaging wider community services, multi-disciplinary professionals and potentially the voluntary sector in order to support service users (Department of Health, 2001). This may be particularly important for service users who have been in inpatient settings for extended periods of time and may be at risk of the negative outcomes associated with this (Pitt, 2011). Furthermore, enabling service users to engage in activities in their own local communities will contribute towards ensuring treatment plans are developed whose gains can be generalised and maintained outside of the inpatient setting (Murphy *et al.,* 1996; Newman & Emerson, 1991).

4.4.8 Developing Community Services

Findings suggested that the development of community services may also be needed in order to reduce the likelihood of inappropriate or avoidable admission, for example as a result of poor access to healthcare (Department of Health, 2009). In order to promote independence, choice, rights and inclusion adults with a learning disability should be admitted to inpatient units as a last resort within a wider care pathway (Department of

Health, 1993, 2007). However, it would appear that community healthcare and local authority services may view inpatient units as respite or transition facilities, as opposed to acute services for the assessment and treatment of mental health problems or exceptional challenging behaviour. The current findings highlighted a number of concerning implications of this, including service users not wanting to leave the unit and the delayed discharge of those for whom placements could not be found.

Consequently, the inappropriate or avoidable admission of service users and lack of community service provision are identified as key areas to be addressed. The provision of teaching and training to local services and development of a skilled workforce is likely to be invaluable in achieving better outcomes for service users (Scior & Longo, 2005). Enhancing the competence of local services and empowering them to feel able to support service users with complex needs will hopefully reduce the view that inpatient admission is an '*easy option*' (Newman & Emerson, 1991, pp.25). Furthermore, raising awareness regarding the purpose of inpatient services and the implications of inappropriate admission is an important implication of this study. It is hoped that dissemination of the current research findings will contribute towards achieving these recommendations, developing training packages for local services and influencing service development.

4.5 Methodological Strengths and Limitations

4.5.1 Methodology and Design

The aim of this research was to obtain a rich, in-depth understanding of service users' experiences in specialist inpatient assessment and treatment units drawing upon multiple perspectives. It was also hoped to integrate these views into a theoretical model for understanding the factors that contributed to service users' experiences. The qualitative Grounded Theory methodology employed was appropriate in meeting these aims and may therefore be considered a strength of the study. However, by obtaining only service users' experiences, different methodological approaches could have been considered. Interpretive Phenomenological Analysis for example, may have yielded different findings and a deeper exploration of service users' lived experiences. However, a limitation identified in relation to previous studies which utilised this approach was that they did not facilitate the development of a theoretical understanding of the processes which contributed to service

users' experiences. In contrast, the current study has enabled the construction of a theoretical model outlining a number of interacting processes which appeared to contribute to service users' experiences of inpatient admission.

The previous research reviewed was criticised for interviewing service users some time after their discharge from inpatient services. In order to address this limitation, the current study recruited service users whilst they were still admitted on the assessment and treatment units. This reduced the potential effect of delayed recall and possible bias introduced as a result of participants having to rely upon their recollection of events that occurred months or years previously. Service users' accounts in this study indicated they were able to recall all aspects of their admission, however the approach used and absence of a retrospective perspective prevented the exploration of service users' experiences of discharge. Furthermore, as service users had been in the assessment and treatment unit for up to a year, the criticisms of previous studies regarding delayed recall may be applicable to the current study in relation to service users' recall of the events surrounding their admission.

The challenges and barriers to achieving service user inclusion in research have been extensively documented and are discussed in section 1.8.2 (Arscott *et al.,* 1998; Chaplin *et al.,* 2009; Gorfin & McGlaughlin, 2005). The current study employed a number of strategies to ensure service users were able to give informed consent, participate in the research and share their views and experiences of inpatient admission. In particular, the researcher used visual communication alongside written information sheets and consent forms to enable service users to provide informed consent in line with recommendations by Nind (2008) and CHANGE (n.d). Furthermore, the recruitment procedures in place ensured service users were approached by a familiar member of the inpatient unit staff team who explained the nature of the research and obtained initial consent. Finally, the researcher took time at the start of the interview to develop a relationship with the service user and used an open, discursive approach to put them at ease in order to foster a comfortable context for service users to engage in the interview process.

4.5.2 Data Collection and Analysis

The use of semi-structured interview schedules may be considered another strength of the study as they facilitated the exploration of a broad range of themes relating to service users' experiences. This approach afforded participants the control to determine the direction and focus of the interview therefore enabling them to highlight specific aspects of admission which they considered to be important. The researcher had little engagement with the existing literature prior to constructing the interview schedules and conducting the interviews thereby introducing minimal bias into the data collection process. By interviewing service users prior to carers and staff the researcher also avoided the introduction of any potential bias or influence to service users' interviews from their knowledge of carers' or staff's perspectives.

In order to further support service users in engaging in the interview process prompts were given and follow up questions used to enable them to expand upon their views. These were used in accordance with the service users' level of expressive communication skills and the researcher was mindful about the use of prompts and the potential influence this might have in shaping service users' responses and the focus of the interview (Nind, 2008). Although each service user required several prompts for more information during their interview, the researcher ensured this was done to follow up on issues service users raised and not to introduce new ideas. Whilst prompting may be considered a criticism of this study, without it the level of service user information yielded would not have been possible.

The presence of staff members during service user interviews may be considered another limitation of the study. In order to ensure the welfare of service users it was felt necessary that they were offered the option to have a familiar member of staff present and each service user chose to accept this offer. It is possible that service users may have been reluctant to disclose negative views as a result of staff presence, however the data obtained does not suggest this to be the case. Furthermore, service users were explicitly told that their treatment or discharge would not be affected by anything they said during their interview. It is hoped that this enabled them to speak openly about their experiences without feeling the need to censor their views

It is also important to consider the possibility that staff may have been reticent to discuss negative views and their accounts might have been influenced by a desire to present a positive image of services. In order to minimise this risk the researcher was cautious to ensure a service user focus throughout the interviews, exploring how service users felt about or experienced various aspects of admission, as opposed to obtaining staff's perceptions of services per se.

It is possible that service users, carers and staff could have expressed conflicting perspectives which would not have facilitated the generation of a cohesive understanding of service users' experiences. A number of precautions relating to data collection and analysis were taken in an attempt to reduce the likelihood of this. In contrast to previous studies, only carers and staff members who service users chose to participate, were considered to know the service users well, and had maintained regular contact during the period of admission were invited to take part. This ensured that carer and staff participants had a well informed perspective on service users' experiences. Furthermore, the similarity and coherence in participants' accounts was assessed during the process of analysis. Each account was considered to provide a useful perspective on service users' experiences with consistent themes running through participants' narratives. It was therefore felt to be appropriate to analyse all interviews as part of one data set and to integrate perspectives within one theoretical model. The consideration of multiple perspectives is therefore regarded as a strength of the current study.

4.5.3 Sample

The recruitment procedures in place for the current study introduced a potential sampling bias that warrants consideration. The study required service managers to undertake the initial identification and approach of potential service user participants. In doing this service managers may have recruited only service users they felt would reflect positively upon their experiences. In addition, the views of service users not considered appropriate for the study have consequently been excluded. This limitation also applies to the previous research reviewed and is difficult to avoid if ethical procedures are to be adhered to (BPS, 2009, 2011). The process of theoretical sampling employed in this study however, enabled the researcher to continue the recruitment processes until a point of theoretical saturation was reached (see section 2.5.5).

It is also important to critique the heterogeneity and generalisability of findings. Whilst qualitative methodologies do not aim to produce findings which can be generalised, the researcher attempted to interview participants who represented a diverse sample from which a theoretical understanding of service users' experiences could be constructed and generalised (Golafshani, 2003). The generation of multiple perspectives facilitated a range of views and experiences to be considered and the sample consisted of service users from different age groups, backgrounds, genders and who were located in different inpatient units. Similarly staff members had extensive experience in working with people with a learning disability, worked across different services and at different levels of seniority. However, carers and staff members were predominantly female which may be considered a limitation. Multiple inpatient settings were approached in an attempt to reduce the likelihood that experiences were unique to one setting. However all settings worked within the same philosophy and management structure, therefore the service contexts to which the research findings can be applied may be limited.

As previously discussed, an inherent restriction in qualitative research with adults with a learning disability is the necessity for them to have a level of cognitive and communication ability which enables them to take part in verbal semi-structured interviews. This methodological limitation also applies to the current study which recruited only service users with a mild learning disability. Consequently, a significant proportion of adults with a learning disability who access specialist inpatient units were excluded. The research findings may therefore only be considered to reflect the experiences of this population of adults within specialist assessment and treatment units. A description of services and participants has been provided in section 2.8 to enable the reader to contextualise the findings which may in part address this limitation.

A sample of eight to ten participants is considered sufficient for the purposes of conducting a grounded theory analysis (Strauss & Corbin, 1998). Although the current study recruited nine participants this reflected only three service users' experiences which may be considered a limitation and further contribute to the caution with which the findings are generalised. However, the use of a small sample is in line with the aims of qualitative methodologies which strive to obtain a rich and in-depth understanding of a phenomenon as has been achieved in this research.

4.5.4 Ensuring Quality

Previous studies have been criticised for providing insufficient detail and transparency regarding how the quality of the research was ensured and the potential influence of the researcher on the data analysis. In order to ensure the quality of the current study the researcher has adhered to the guidelines proposed by Elliot *et al*. (1999) described in section 2.6 and clearly documented the analytic processes.

An example of this is the researcher's commitment to grounding the theory in the data gathered. Using the process of constant comparison described in section 2.5.3, a 'grounded' theory was constructed by moving constantly between the data and the process of analysis. This process was recorded to protect against it becoming overly biased by the researcher's own interpretation. Furthermore, credibility checks were undertaken with the researcher's supervisors during the theory construction to ensure the categories and concepts that were proposed closely reflected the experiences described by participants (see section 2.6.4). Finally, quotes have been provided in Chapter 3 to enable the reader to fully understand the theory constructed.

Unfortunately it wasn't possible to carry out credibility checking with original participants and this could be considered a limitation of the study. A focus group with participants would have enabled the researcher to check whether the research findings accurately reflected the accounts service users, carers and staff provided and captured an integrated theory of participants' perspectives. This would have been a useful process within the analysis to strengthen the quality of the research however this was not undertaken due to the limited timescale.

4.6 Recommendations for Further Research

The findings from the current study provide a valuable insight into the experiences of adults with a learning disability in specialist inpatient assessment and treatment units. The findings, implications and limitations of the research indicate several potential areas for future research.

As this study employed a relatively small sample and the results are limited in their generalizability, it will be important that further research is undertaken in this area to

increase the sample size overall. Furthermore, research is needed to explore the experiences of adults with moderate and severe learning disabilities. The current study suggests that, in cases where service users are limited in their ability to engage in the research process themselves, this may be achieved using the perspectives of carers and staff who know the service user well.

Further investigation within this area of research may also be useful to explore the theory constructed in the current study. In particular, further research should seek to consider more explicitly the links between psychological processes involved in the construction of understanding and meaning and service users' experiences of admission. The focus of the current study was broad, however findings suggest that factors related to service users' sense of self; relationships with others; feelings of safety within the context of these relationships and the inpatient unit; and sense of control and inclusion may interact to influence their experience. The specific nature of these interactions cannot be determined from the results obtained in the current study, however more focused research may provide greater insight and understanding into how these factors relate to one another and influence service users' experiences. Furthermore, the concept of 'understanding and meaning' was grounded most heavily within staff's and carers' accounts of service users' experiences. Further exploration of this concept may therefore be warranted in order to extend our knowledge of the impact of staff beliefs upon service users' experiences and the construction of shared understanding specifically from service users' perspectives. It may also be hypothesised that the model proposed by this study encapsulates both protective and vulnerability factors which contribute to positive and negative experiences of admission. Quantitative research may facilitate a more in-depth exploration of these factors in order to identify which are most significant in their contribution.

The application of social constructionist, systemic and attachment theories in the field of learning disabilities and challenging behaviour remains limited. However, the current study has shown that these theoretical frameworks can be meaningfully applied to this field in order to support service user inclusion in research and provide useful models from which to make sense of their experiences. Further consideration from these theoretical perspectives of the experiences of adults with a learning disability within a range of inpatient and residential settings is therefore recommended.

There has been much debate regarding the effectiveness and different experiences across specialist and mainstream service provision. No previous research has been identified exploring the experiences of adults with a learning disability specifically in specialist inpatient units. Although the current study may contribute to this debate it would be helpful to replicate this study in other settings to expand upon the findings across different service models. This would enable findings to be compared and potentially strengthen the influence of the current study on service development.

4.7 Conclusions

The current study provided a rich, in-depth exploration of the experiences of adults with a learning disability in specialist inpatient assessment and treatment units. Whilst there is a growing body of research exploring the experiences of service users in inpatient settings, this was the first to explore experiences specifically in specialist units and to draw upon different perspectives to achieve this.

The findings from the current study suggested that service users' experiences were influenced by factors relating to procedural aspects of admission as well as a number of psychological processes. Systemic and attachment theories are considered to provide useful frameworks within which to understand the factors influencing service users' experiences and the impact of patterns of interactions and relationships upon this.

Several clinical implications were highlighted from the findings including the need to create a context within inpatient services for shared understanding between staff, carers and service users to be constructed. Recommendations were also made for supporting staff to develop meaningful relationships with service users and provide emotional support, as well as for maintaining family relationships. The importance of enhancing the provision of therapeutic activities and implications of developing vital links with community services were also discussed. The current study has a number of strengths, however limitations have also been highlighted with possible directions for future research outlined.

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APPENDICES

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Appendix 1: Summary of Literature Search Process

Databases searched:	EMBASE	1974 – 2012 (Jan week 2)
	Ovid Medline (R)	1946 – 2012 (Jan week 2
	PsycINFO	1806 – 2012 (Jan week 2)

Learning disabilit* OR
Intellectual disabilit*
AND
Inpatient OR In-patient

Learning disabilit* OR
Intellectual disabilit*
AND
Mental Health OR Psychiatric
AND
Service user* OR Experience*
OR View*

Learning disabilit* OR
Intellectual disabilit*
AND
Challenging Behaviour
AND
Service user* OR Experience*
OR View*

EMBASE – 134
Medline – 140
PsycINFO – 93
Total – 367
(excluding duplicates)

EMBASE – 298
Medline – 205
PsycINFO – 413
Total – 916
(excluding duplicates)

EMBASE – 49
Medline – 4
PsycINFO - 50
Total – 103
(including duplicates)

Abstracts Reviewed and Exclusion Criteria Applied*

EMBASE – 24
Medline – 0
PsycINFO – 18
Total – 42

EMBASE – 12
Medline – 3
PsycINFO – 19
Total – 34

EMBASE – 0
Medline – 0
PsycINFO – 0
Total – 0 (High % duplicates)

Additional papers identified
manually** - 11

Total relevant papers identified -
87

Epidemiology/prevalence
LD/CB/MH - 4

Obtaining service users views -
10

Service development context - 17

Inpatient services (types, uses,
effectiveness) - 28

Service user views and experiences
(excluding inpatient services) - 18

**Views and experiences of inpatient services – 10
***Retained for systematic review**

*Exclusion criteria:	Not learning disability focused	Physical health focused
Child not adult	Forensic inpatient focused	Non UK service focused
Community focused (and not su experience/view focused)		Duplicate paper

**Additional papers identified through a review of the references of key articles, key journals (Journal of Applied Research in Intellectual Disabilities; Advances in Mental Health and Learning Disabilities), Cochrane review, recommendations from experts within the field and key policies

Appendix 2: Literature Review Table

Critical appraisal of research studies based on frameworks from Spencer et al (2003) and Law et al, (1998):

- Study has clear aims and objectives / statement of purpose
- Previous literature is reviewed and provides a rationale for study
- Design is clear and appropriate
- Context and setting are clearly described
- Sampling and participant characterises are clear and suitable

- Data collection and analysis is systematic and clearly described
- Trustworthiness: results are supported by the data and steps taken to ensure credibility / triangulation / reflexivity
- Study contributes to existing knowledge / practice and addresses original aims

Reference	Aim & Design	Service Setting	Number of Participants	Participant Demographics	Data Collection & Analysis Method	Format of Findings	Limitations
Murphy, et al. (1996)	To obtain service users evaluation of current quality of life and views of previous inpatient admission. No design specified	Specialist inpatient service (limited description given)	25 service users interviewed; 26 completed questionnaire. 25 carers completed questionnaire All service users who left unit during given period were considered eligible	Recruitment up to 2 years post discharge (mean 56.5 months). Level of LD and reason for admission unknown 9 women, 17 men Mean age 35.6 years	Semi-structured interviews and quality of life questionnaire. No method of analysis specified. Some evidence of credibility/ reliability/ validity checking	Percentage of service users who described given experience is reported and how experience was rated (positive or negative)	Interview data not translated into meaningful themes (descriptive not interpretive) Duration since discharge (although some evidence of recall issues being addressed) Level of LD unknown (generalisability)
Longo & Scior (2004)	To explore service user and carer experiences of inpatient admission using qualitative design Qualitative	Mainstream and specialist service provision (3 ATUs) (London)	33 service users eligible – 14 maintream, 15 specialist took part. 26 carers (family and paid) approached – 10 mainstream, 10 specialist took part	Recruited up to 12 months post discharge (some still inpatient). All mild-moderate LD Similar demographics across settings. 9 voluntary, 6 detained (specialist; equal in mainstream)	Semi-structured interview (all aspects of admission) IPA Thorough description of analysis and evidence of credibility checking	Themes presented with quotes to support	Limited geographical area Limited review of previous literature Limited consideration of study limitations

Scior & Longo (2005)	To explore service user and carer experiences of inpatient admission using qualitative design Qualitative	Mainstream and specialist service provision (3 ATUs) (London)	33 service users eligible – 14 mainstream, 15 specialist took part 26 carers (family and paid) approached – 10 mainstream, 10 specialist took part	Recruited up to 12 months post discharge (some still inpatient). All mild-moderate LD Similar demographics across settings. 9 voluntary, 6 detained (specialist; equal in mainstream)	Semi-structured interview (all aspects of admission) IPA Thorough description of analysis and evidence of credibility checking	Themes presented with quotes to support	Limited geographical area
Chaplin, *et al.* (2006)	To explore prevalence and experience of violence on inpatient units Audit design	47 UK wide specialist inpatient units (limited description)	585 staff 157 service users Staff and service users in all UK trusts eligible.	Unknown	Closed question questionnaire and some qualitative questions Descriptive statistical analysis and Thematic analysis	Descriptive statistics Themes	Specific focus on prevalence and experience of violence. Limited demographic information known Data did not provide meaningful understanding of experience.
Vos, *et al.* (2007)	To examine subjective experiences of service users in mainstream psychiatric wards and identify implications for service provision Survey Design	Mainstream psychiatric ward (limited description given)	8 service users eligible, 6 consented All service users admitted to unit during given period were considered eligible.	Recruitment during and after admission. All mild LD. 2 informal, remainder detained 16-44 years of age 5 women, 3 men (participant demographics not stated)	Semi-structured questionnaire No statistical analysis possible No evidence of credibility/ reliability/ validity/ checking	Percentage of service users who experienced specified experience on questionnaire reported with descriptive statistics	Descriptive not interpretive Small sample size. Lack of data analysis Only service users with Mild LD (generalisability)

Samuels, *et al.* (2007)	To investigate staff and carer views on new integrated service provision

Qualitative design | Integrated service provision (dedicated beds in mainstream mental health ward) | 12 professionals (from community support teams) and 8 carers (4 family, 4 paid)

Sampling criteria unclear | 11 women, 9 men | Semi-structured interview

Thematic approach to analysis: Qualrus

Independent coding and external validity/ credibility checking. Some evidence of reflexivity | Themes with number of participants commenting on each theme reported: few quotes given | Approach to thematic analysis not specified

Level of involvement professional/carer had with unit/service user is unclear |
| **Parkes, *et al.* (2007) – Study relates to Samuels, *et al.* (2007)** | To obtain views of service users on mainstream inpatient service admission and on integrated service provision following service development

Qualitative design | Mainstream psychiatric ward and integrated service (dedicated beds in mainstream mental health ward) | All service users admitted to unit during given period were considered eligible

Phase 1: 15 service users eligible – 12 interviewed

Phase 2: 23 service users eligible – 19 interviewed

. | Recruitment up to 3 years post discharge

Level of LD not specified

6 women, 6 men. 26-54 years of age (41 mean). Admitted 1-78 weeks (mean 15). 7 voluntary, 5 detained.

12 women, 7 men. 20-68 years of age (mean 39). Admitted 1-24 weeks (mean 9). 11 voluntary, 8 detained. | Peer reviewed semi-structured interview

Thematic approach to analysis: Qualrus

Some evidence of multiple author coding and credibility checking | Themes reported with supporting quotes given. | Approach to thematic analysis not specified

Level of LD not stated (generalisability) |
| **Donner, *et al.* (2010)** | To explore service user, carer and service provider views of mainstream service provision | 5 different mainstream inpatient units in 2 locality areas | 26 service users eligible – 11 consented to take part or carer to take part.

15 interviews – 9 service users, 9 family carers, 4 community | Recruited up to 2 years post discharge (range 2-52 weeks: all discharged)

No level of LD specified | Semi-structured interview (pre admission, admission and post discharge). Combined interviews

Focus group with service providers | Themes presented with quotes to support | No level of LD specified

No providers from mental health services took part in focus group.

Possible sampling bias |

	Qualitative		nurses 7 service providers (members of community ID team) (focus group)	30-55 years of age. 5 women, 6 men.	IPA – case by case analysis. Thorough description and evidence of credibility checking		by service providers Possible censorship in combined interviews
Bonell, *et al.* (2011)	To elicit the views of family carers of service users placed in out of area specialist services Qualitative	18 out of area specialist in patient residential services (7 NHS, 11 private) used by 3 London boroughs	27 family members eligible – 16 consented (11 parents, 3 siblings, 2 partner/spouse)	2 women, 14 men. Mean age 35 years Service users: Level of LD: 69% mild/borderline 12% moderate 19% severe/profound 7 voluntary, 9 detained	Semi-structured interview covering broad range of areas Thematic analysis Thorough description of analysis and evidence of credibility checking	Themes presented with quotes to support	Residential service not acute facility Possible bias and influence from researcher / trust agenda
Chinn, *et al.* (2011) Study relates to Bonell, *et al.* (2011)	To elicit the views of service users placed in out of area specialist services Qualitative	18 out of area specialist in patient residential services (7 NHS, 11 private) used by 3 London boroughs	26 service users eligible – 17 interviewed All service users in out of area placements considered eligible. 9 not approached due to concerns raised by Consultant Psychiatrist	Interviewed during 'admission' Admitted 2-120 months (mean 30 months) 80% Mild LD 75% Detained 4 women, 13 men Mean age 34 years	Semi-structured interview covering range of aspects of admission and service provision Thematic analysis Thorough description of analysis and evidence of credibility checking	Themes presented with quotes to support	Residential service not acute facility Views of those excluded by Psychiatrist not heard. Mostly mild LD (generalizability) No control group or comparison

Appendix 3: Extract of Memos

Definitions:

FEELING SAFE: references to service users feeling safe from threats outside of the unit and safe from threats within the unit. References to service users viewing the assessment and treatment unit as a safe or secure base.

Links to: being vulnerable, being assaulted on the unit, restrictions to maintain safety

CLARIFYING UNDERSTANDING: references to staff checking out service users' understanding of what has been said to them or what is happening.

Links to: explanations, service user understanding, misinterpretation

Categories and connections:
During the coding process categories were linked and renamed using NVivo to manage this process. Some examples are given below:

- 'Being like staff' – renamed 'acting like staff' as this better captured participants' views of service users taking on the role of staff members

- Reason for admission – clarified throughout transcripts whether participants talked about the official 'reason for admission' or service users' 'beliefs about reason for admission' (re-coded) – linked beliefs about admission to 'view of unit'

- Consistency – split into 'approach to working with service user' and 'consistent communication' as latter more closely linked with 'boundaries' and 'staff working together'

Theory development:
In relation to how 'theory' might hang together I've noticed that categories arising seem to fit with bronfenbrenners ecological circles with regards to reflecting individual factors that service users bring / staff factors / organisational or unit based factors / other service user factors / family factors....and then how these relate to each other and interact to influence the service users experience.

Looking at relationships between staff / family / service users / LD culture / political framework fits with constructivist epistemology of qualitative methodology.

Appendix 4: Reflective Diary Extract

Developing ideas:

14th March:
There are so many ideas?! How do I know where to start or what to focus on? The area of service users' experiences is so under researched it feels like I could do anything. I'm still interested in family's experiences but it also feels that staff would have a lot to offer and then [clinical supervisor] has quantitative data I could use. Am feeling very overwhelmed with ideas.

Interviews:

13th August:
Having just completed my first service user interview I've realised I conducted the interview with an assumption that she would not be able to give me rich, elaborate answers therefore I'd jump in with another question or an interpretation or suggestion too quickly. I hadn't thought I'd have that assumption but I think I might have under estimated her abilities to engage in the interview process and lead it herself rather than relying on me to guide and direct it.

17th August:
I have my second interview planned and am really hoping I can take what I've learnt from the first interview and apply it. In order for my methodology to be most effective I need rich information so I need to offer participants the 'space' to tell their story or that of the service user.

Cross roads:

5th September:
It's been a stressful week! Having done two service user and one carer interviews I'm feeling on one hand like I have loads of information already and on the other like I have no idea what I have. I've reached a cross roads where I have to decide whether to recruit participant triads or whether to just do service users and carers. I don't know how changing my research now will impact upon what I can conclude at a later date though. My option is to ditch the staff participant group but this really feels like it changes the systemic approach to the research as it reduces the number of perspectives obtained. Eek…what to do?!

Analysis

28th October:
The analysis process begins!!! I initially generated 59 codes with 99 references but yesterday refined the codes I had by comparing similar codes and checking that the code names reflected what was said and not what I was interpreting. Think on a number of occasions I had coded at quite an abstract level which maybe reflected the fact that I have already begun to think about themes and hypotheses; so I refined my code names in line with this. I'm starting to understand the iterative process that grounded theory talks about as I move between the transcript and the codes, between the codes and the themes/hypotheses I have, and between the codes. That was hard work enough with 1

transcript so goodness knows when I have to add another 1 into the mix….and then another 7!!!

11th Nov:
I've changed how I'm approaching the data. I was finding that doing the coding through NVivo wasn't enabling me to see the bigger picture in the data so I've started reading hard copies of the transcripts and noting down codes then plan to transfer these into NVivo to store the analysis. I'm definitely feeling closer to the data and getting a better sense of it by coding on the hard copy. It's giving me more of an understanding of the data as a whole rather than coding each line in isolation of the context

10th January:
Happy New Year!! Well I feel like I'm well and truly in the thick of it now. I have post-it notes permanently attached to me and I'm scribbling concepts and category links almost daily. I think the analysis is going well but there are sooooooo many categories and I need to get this initial stage of the analysis done soon so that I can start refining my categories and have a more manageable amount of analysis to handle.

1st April:
I'm writing up and still amending my results?!? Every time I look at the data I notice something new and then when I discuss this with my supervisor something new seems to be constructed again. It's so useful to keep reflecting upon my concepts and categories and checking out that they fit together but it does leave me wondering whether this process will ever end….

Appendix 5: Transcript Extract

Interview with Roger, staff member re: Alan

(margin note: Reason for admission)

(margin note: Wants vs needs)

(margin note: Talking)

(margin note: Staff commitments)

P)   First week, always the first week when he's come in apart from this time because it was for a different reason, it was all attitude. None of it was his fault. So like I say, we'd be having a chat, he has access to talk time every day, not when he wants it obviously, but every day he might say to me 'can we have a chat?' 'I haven't got time now,' he's usually ask at 1 o'clock just before handover but I'd say 'I'll see you before I go home' and I'll finish at half past 2, before now I've gone in at 20 past 2. I'll say 'right don't worry about the time' because he knows I finish at half past 2, 'it doesn't matter. Whats the problem? I told you I'll see you and explain when things are happening. I know when you're busy. You don't have to talk to me you can talk to anybody.' 'I know but I like to talk to you.' Because I think probably because I try to give him the explanations.

(margin note: Explanations)

I)   Is that important to Alan do you think, having the explanation and knowing what's happening and why things are like they are?

(margin note: Getting to know/understand SU)

(margin note: Routine)

P)   Well, just knowing why. I explain to him and he'll say 'yes, yes, yes' to anything. So I always say to him 'now you tell me what I just told you.' And he goes 'um,.....' So I say 'if you don't understand tell me you don't understand and I'll try to explain it another way.' Because this is what has happened a lot, I think especially in that placement, they say something to him and ask 'do you understand?' And he says 'yes.' So they walk away and he hasn't got a clue. Because working with people who are less able than Alan anyway you know you've got to try a few different ways to try to figure out what they understand. And Alan, because he talks so well, people will say 'you say to him, he knows, it's over.' But he doesn't always. If he doesn't understand he might not understand why but half the time he doesn't understand. So that's why I always say to him 'now what did I say to you?' 'I don't know.' 'what do you think I said to you?' that's what I follow it up with then to see what he thinks I said which I think is more important than him understanding exactly what I said. It's more important for me to know what he thinks I said because he might get the wrong end of the stick. Like, he has a timetable, he likes his weekly timetable. So it'll say Tuesday morning, always Tuesday morning because the TV choice is out on a Tuesday,

(margin note: Clarifying understanding)

(margin note: Expectations too high)

(margin note: Clarifying understanding)

(margin note: misunderstanding)

Interview with Roger, staff member re: Alan

Routine + predictability

Tuesday morning personal shopping 10 o'clock. So he'll come out at 10 o'clock and he'll have his coat and shoes on and he'll say 'I've got shopping now'. I'll say 'hand on, what do we always say? 10 o'clock or as soon as the staff can do it.' Because he'll still go out that morning but of course if we're in the middle of something else he might not actually go out until 11. So what I normally do then is, because he'll ask in the morning who's taking him when he gets up, I'll say 'its me this morning.' But if it's me I always say 'it's me this morning but I will give you a shout when we're going.' Because I've got other things I've got to do as well and if I've got nothing going I'll say 'right we'll be going about 10 o'clock,' or I'll say 'we'll go out as soon as you've had your drink,' which they have their mid morning drink and fruit at half past 10.

Keeping s.u. informed.

Being Prepared. Proactive

P)   So, if I'm free for 10 I normally say that then because if we're out then he's not gonna miss his drink. So I say 'we'll do out at soon as you've had your drink' so he's got the perfect timeline anything crops up I've got that extra bit of time to deal with it before we go. And sometimes I've even said 'I can't go with you now I've got something else to do but so and so else is gonna take you instead.'

Changes to Plans.

I)   How does Alan experience having to wait or things being cancelled do you think? What's his experience of that been on the unit?

Unpredictable events

Unit capacity

frustration

challenging Behaviour

P)   At the moment now, not a lot because we're quite quiet but over the years when he's been with us he's had a lot of disappointments. Not so much through his own doing. We're an 8 bedded unit we tend to work 4 staff. If we have someone in whose exceptionally challenging and something, and they have an aggressive outburst, there's no way I can turn round, if we have 2 people dealing with that person, and have one person take Alan out and leave 1 person dealing with the other 6. So, I mean before now he've marched back off to his room 'I can't go out now' and he's played up.

Disappointment

Staffing demands

Disappointment

Appendix 6

<u>Appendix 6: Research & Development Approval Letters</u>

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

Ysbyty Athrofaol Cymru
University Hospital of Wales

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Cardiff, CF14 4XW   Caerdydd, CF14 4XW
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Fax 029 2074 3838   Ffacs 029 2074 3838
Minicom 029 2074 3632 Minicom 029 2074 3632

Eich cyf/Your ref
Ein cyf/Our ref
Welsh Health Telephone Network 1872
Direct line/Llinell uniongyrchol

Tel: 029 20746986
Fax: 029 20745311
CAV_Research.Development@wales.nhs.uk

From: Professor JI Bisson
R&D Director
R&D Office, 2nd Floor TB2
University Hospital of Wales
Cardiff
CF14 4XW

13 July 2011

Miss Hayley Hill
Trainee Clinical Psychologist
Archway House
77 Ty Glas Avenue
Llanishen
Cardiff
CF14 5DX

Dear Miss Hill

Project ID : 11/MEH/5121 : The Experience Of Adults With Learning Disabilities In Specialist Inpatients Assessment And Treatment Units

Further to recent correspondence regarding the above project, I am now happy to confirm receipt of:

- Evidence of favourable opinion from the relevant NHS Research Ethics Committee
- Revised documentation as required by the REC in order to obtain favourable opinion
- Evidence of appropriate GCP training for the CI / PI / delegated researchers

The following amended documentation is approved for use with this study:

Documents	Version	Date
Favourable Opinion from South East Wales REC		30 June 2011
Staff/Carer Participant Information Sheet	2.0	22 June 2011
Service User Information Sheet	4.0	22 June 2011
Service User Consent Form	3.0	22 June 2011
Staff/Carer Consent Form	3.0	22 June 2011

Page 1 of 2

Version 1.0. 09.06.10
Bwrdd Iechyd Prifysgol Caerdydd a'r Fro yw enw gweithredol Bwrdd Iechyd Lleol Prifysgol Caerdydd a'r Fro
Cardiff and Vale University Health Board is the operational name of Cardiff and Vale University Local Health Board

UHW129X

Please accept this letter as confirmation of sponsorship by Cardiff and Vale UHB and permission for the project to begin.

May I take this opportunity to wish you success with the project, and to remind you that as Principal Investigator you are required to:

- Ensure that all members of the research team undertake the project in accordance with ICH-GCP and adhere to the protocol as approved by the Research Ethics Committee
- Inform the R&D Office if any external or additional funding is awarded for this project in the future
- Inform the R&D Office of any amendments relating to the protocol, including personnel changes and amendments to the actual or anticipated start and end dates
- Complete any documentation sent to you by the R&D Office or University Research and Commercial Division regarding this project
- Ensure that adverse event reporting is in accordance with the UHB adopted Cardiff and Vale NHS Trust Policy and Procedure for Reporting Research-Related Adverse Events (refs 164 & 174) and Incident Reporting and Investigation (ref 108)
- Ensure that the research complies with the Data Protection Act 1998
- Ensure that arrangements for continued storage or use of human tissue samples at the end of the approved research project comply with the Human Tissue Act, 2004 (for further information please contact Sharon Orton, HTA Coordinator OrtonS@cf.ac.uk).

If you require any further information or assistance, please do not hesitate to contact staff in the R&D Office.

Yours sincerely,

Professor Jonathan I Bisson
Cardiff and Vale University Local Health Board R&D Director

CC   R&D Lead Prof Nick Craddock

GIG CYMRU NHS WALES | Bwrdd Iechyd Prifysgol Caerdydd a'r Fro
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From: Professor JI Bisson
          R&D Director
          R&D Office, 2nd floor TB2
          University Hospital of Wales
          Cardiff
          CF14 4XW

18 May 2011

Miss Hayley Hill
Trainee Clinical Psychologist
Archway House
77 Ty Glas Avenue
Llanishen
Cardiff
Cf14 5dx

Dear Miss Hill

Project ID : 11/MEH/5121 : The Experience Of Adults With Learning Disabilities In Specialist Inpatients Assessment And Treatment Units

Thank you for your recent communication regarding the above project, which was reviewed on 18 May 2011 by the Chair of the Cardiff and Vale Research Review Service (CaRRS).

Documents submitted for review were:

Document	Version	Date
NHS RD Form	3.1	Received 06/05/11
SSI Form	3.1	Received 06/05/11
Protocol	1.0	09/02/11
Semi Structured Interviews: Staff/Carer	3.0	23/03/11
Participant Information Sheet: Staff/Carer	1.0	09/02/11
Participant Consent Form: Staff/Carer	2.0	09/02/11
Semi Structured Interviews: Service User	2.0	23/03/11
Participant Information Sheet: Service User	3.0	18/04/11
Participant Consent Form: Service User	2.0	10/03/11

I am pleased to inform you that the Chair had no objection to your proposal.

R&D approval and final acceptance of sponsorship by Cardiff and Vale UHB is now subject to the following:

- Evidence of favourable opinion from the relevant NHS Research Ethics Committee

Once the above is in place, an R&D approval letter will be issued. You should not begin your project before receiving this written confirmation from the R&D Office.

Please ensure that you notify R&D if any changes to your protocol or study documents are required in order to obtain a favourable opinion from the Research Ethics Committee.

If you require any further information or assistance, please do not hesitate to contact the staff in the R&D Office.

Yours sincerely,

Professor Jonathan I Bisson
Chair of the Cardiff and Vale Research Review Service (CaRRS)

CC   R&D Lead Prof Nick Craddock

[ENCS] Obtaining a sponsorship signature - guidelines

Appendix 7: Ethics Approval Letters

NISCHR

Uned Cydlynu Caniatâd **PCU** Permissions Co-ordinating Unit

South East Wales Research Ethics Committee
Sixth Floor, Churchill House
17 Churchill Way
Cardiff CF10 2TW

Telephone : 029 2037 6823

30 June 2011

Mrs Hayley Hill
Trainee Clinical Psychologist
Cardiff and Vale University Health Board
South Wales Doctoral Programme in
Clinical Psychology, Archway House
77 Ty Glas Ave, Llanishen, Cardiff
CF14 5DX

Dear Mrs Hill

Study title: **The experiences of adults with learning disabilities in specialist inpatient assessment and treatment units**

REC reference: 11/WA/0160

Thank you for your letter of 24 June 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair, Dr K Craig.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

<u>Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.</u>

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

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

Document	Version	Date
Interview Schedules/Topic Guides	2 - Service User	23 March 2011
Interview Schedules/Topic Guides	2 - Staff / Carer	23 March 2011
Investigator CV	H Hill	20 May 2011
Investigator CV	R Jenkins	23 March 2011
Participant Consent Form: Service User	3	22 June 2011
Participant Consent Form: Staff/Carer	3	22 June 2011
Participant Information Sheet: Service User	4	22 June 2011
Participant Information Sheet: Staff/Carer	2	22 June 2011
Protocol	1	09 February 2011
REC application	IRAS 3.1	23 May 2011
Referees or other scientific critique report	CaRRS	18 May 2011

Response to Request for Further Information		24 June 2011

Statement of compliance

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

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

> Notifying substantial amendments
> Adding new sites and investigators
> Progress and safety reports
> Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

11/WA/0160	Please quote this number on all correspondence

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

Yours sincerely

Dr K J Craig
Chair

Email: jagit.sidhu@bsc.wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers" *[SL-AR2]*
Copy to: *R&D Office for Cardiff & Vale NHS Trust*

NISCHR

Uned Cydlynu Caniatâd

PCU
Permissions Co-ordinating Unit

South East Wales Research Ethics Committee
Sixth Floor, Churchill House
17 Churchill Way
Cardiff CF10 2TW

Telephone : 029 2037 6823

09 June 2011

Mrs Hayley Hill
Trainee Clinical Psychologist
South Wales Doctoral Programme in
Clinical Psychology, Archway House
77 Ty Glas Ave, Llanishen, Cardiff
CF14 5DX

Dear Mrs Hill

Study Title:	**The experiences of adults with learning disabilities in specialist inpatient assessment and treatment units**
REC reference number:	**11/WA/0160**

The South East Wales Research Ethics Committee - Panel D reviewed the above application at their meeting held on the 9th June 2011.

Thank you for attending to discuss the study, the clarification that you provided was most helpful.

Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
Interview Schedules/Topic Guides	2 - Service User	23 March 2011
Interview Schedules/Topic Guides	2 - Staff / Carer	23 March 2011
Investigator CV	H Hill	20 May 2011
Investigator CV	R Jenkins	23 March 2011
Participant Consent Form: Service User	2	10 March 2011
Participant Consent Form: Staff / Carer	2	09 February 2011
Participant Information Sheet: Service User	3	18 April 2011
Participant Information Sheet: Staff / Carer	1	09 February 2011
Protocol	1	09 February 2011
REC application	IRAS 3.1	23 May 2011
Referees or other scientific critique report	CaRRS	18 May 2011

Provisional opinion

The Committee noted that this was a single site qualitative study with the main objective being to explore the experiences of adults with learning disabilities in specialist inpatient assessment and treatment units.

The Committee noted that the study was being carried out for an educational qualification.

The Committee noted that approximately 36 service users will be recruited into the study who meet the eligibility criteria.

The Committee noted that potential participants would initially be identified and approached by healthcare professionals involved in their care.

The Committee noted that potential participants will be provided with written information about the purpose of the study, why they have been invited to participate, who is conducting the research, how the data would be used and what participation will require of them. They will also be given the opportunity to ask any questions about the study. Written consent will be obtained prior to participation in the study. It will be made clear throughout the study that participation is entirely voluntary and that they can withdraw at any point for any reason.

The Committee noted that no intervention or procedure, which would normally be considered a part of routine care, would be withheld from participants.

The Committee noted that the Cardiff University would be acting as sponsor for the above study in accordance with the Research Governance Framework.

The Committee noted that the sponsor had signed the declaration in the application form to confirm that an appropriate process of scientific critique had demonstrated that the research proposal is worthwhile and of high scientific quality and that the necessary insurance or indemnity arrangements will be in place prior to commencement of the research.

The Committee noted from Q (A43) of the application form that study data would be stored for less than 3 months after the end of the study. The Committee asked that you ensure that all data is stored and destroyed in line with the Data Protection Act (1998).

The Committee noted that the start date on the application was incorrect and asked that the study does not commence until all relevant approvals are in place.

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

The Committee delegated authority to confirm its final opinion on the application to the Chair.

Further information or clarification required

1. The Committee noted that you had detailed in the information sheets that confidentiality would be broken if you became aware of potential risk to the participant or another person. The Committee asked that you also explain in the information sheet how this would be managed.

1.1 The Committee noted the information sheet for staff/carers and were of the view that the information sheet may be too technical for carers to comprehend. The Committee therefore advised that you simplify the information sheet or provide a separate information sheet for carers.

2. The consent form should be amended in the Point 1 should make reference to the version number and date of the corresponding information sheet.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact Mrs J Sidhu, Co-ordinator on 02920 376822.

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 07 October 2011.

Membership of the Committee

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

Statement of compliance

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

11/WA/0160	**Please quote this number on all correspondence**

Yours sincerely

Dr K J Craig
Chair

Email: jagit.sidhu@bsc.wales.nhs.uk

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

Copy to: *Professor Jonathon Bisson*
Professor Jonathon Bisson

South East Wales Research Ethics Committee - Panel D
Attendance at Committee meeting on 09 June 2011

Committee Members:

Name	Profession	Present	Notes
Dr Roshan Adappa	Consultant / Expert Member	No	
Dr K J Craig	Nurse	Yes	
Doctor Peter Dewland	Consultant	Yes	
Ms B Edwards	Lay Member	No	
Mrs M Evans	Lay Member	No	
Mr Robert Hall	Lay Member	Yes	
Dr Deidre Jones	Lay Member	Yes	
Dr S Logan	Consultant Anaesthetist	Yes	
Mrs A McGowan	Lay Member	Yes	
Dr Richard Sturgess	Pharmacist	No	
Ms K Walker	Pharmacist	Yes	
Sir D Walters	Alternate Vice Chair and Lay Member	No	
Dr S White	Consultant Physician Geriatrics	Yes	

Also in attendance:

Name	Position (or reason for attending)
Mrs J Sidhu	Co-ordinator

Appendix 8: Host Health Board Research & Development Approval Letter

Research & Development Department **NHS**

Please reply to: Research & Development Department
Clinical Research Unit
Abertawe Bro Morgannwg University
Health Board
Morriston Hospital
SWANSEA
SA6 6NL

Telephone: 01792 704056
Fax:
E-mail: jemma.hughes@wales.nhs.uk

Mrs Hayley Hill, 27 June 2011
Trainee Clinical Psychologist
Cardiff & Vale University Health Board
South Wales Doctoral Programme in Clinical Psychology
Archway House, 77 Ty Glas Avenue,
Llanishen, CARDIFF
CF14 5DX

Dear Mrs Hill,

ID: S11Psyc1017   **The experiences of adults with learning disabilities in specialist inpatient assessment and treatment units**

I am pleased to inform you that the above research study, which you recently submitted for review, has been approved by Abertawe Bro Morgannwg University Health Board.

Approval has been granted on condition of a favourable ethical opinion being granted by South East Wales REC. Please forward a copy of the ethics approval letter(and any updated document versions) to the R&D Department.

Cardiff University is Sponsor for this study, as required under the Research Governance Framework.

As a requirement of the Research Governance Framework, all research studies registered as active within ABM University Health Board will be subject to a randomised audit procedure to ensure appropriate standards of Research Governance (RG) and Good Clinical Practice (GCP) are being applied throughout the conduct of the research. Research Active Personnel must therefore ensure they familiarise themselves with the standards of RG and GCP. For clinical trials of investigational medicinal products, please ensure all members of the research team are up to date or have attended recent training in GCP. Details of GCP training are available from the R&D Office.

Researchers employed by ABM University Health Board, including those holding Honorary Contract status are indemnified against actions for negligent harm via standard arrangements with Welsh Risk Pool (WRP). Provision for 'no-fault' compensation is limited under the scheme and is only available on an ex gratia, discretionary basis where the Sponsor is a NHS Organisation.

ABM University Health Board reserves the right to suspend approval of any research study where deviation from appropriate RG & GCP standards is uncovered.

Please ensure that any changes made to the study are submitted to the R&D Department for review and approval, including:

- Notification of Amendment (copy of all documentation sent to Ethics is also required by R&D)
- Adding new Sites and Investigators(CV's to be included)
- Progress and Safety Reports
- Notifying of the End of study

May I take this opportunity to wish you well in undertaking the research. We will write to you in the future to request updates on the progress of the research and look forward to receiving outcomes of the study.

Yours sincerely

Professor Stephen Bain
Assistant Medical Director (R&D)
Abertawe Bro Morgannwg University Health Board

Appendix 9: Service User Information Sheet

VERSION 4 22/06/2011

Service User Information Sheet

- My name is Hayley Hill
 I am training to be a Clinical Psychologist

- I would like to invite you to take part in a research project I am doing

- Research helps us find out what people with learning disabilities think

- This leaflet will tell you about the project

  Why have you been asked to take part?

- I would like to talk with you about your time in an assessment and treatment unit

- This will take about 1 hour
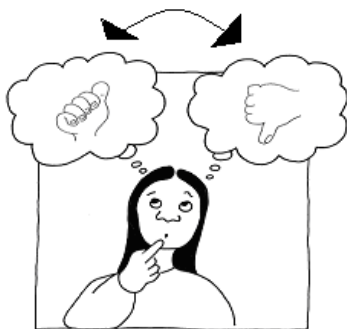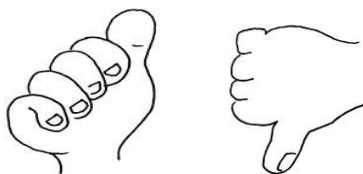
Who else will take part?

- I would like to talk to a staff member from your key work team

- I would also like to talk to someone from your family or a paid carer

- If you don't want me to speak to anyone else about you that is fine.

- Other adults in assessment and treatment units will also be asked to take part

Do you have to take part?

- It is your choice to take part

- If you do not want to talk to me that is ok

- Taking part will not affect your treatment or discharge

- If you agree to meet with me but change your mind that is ok. You can change your mind at any time
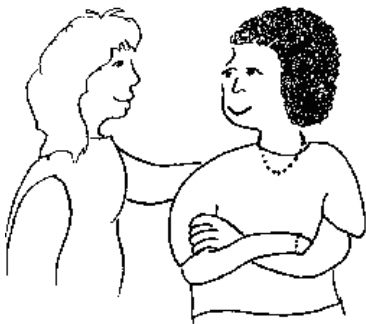
Will taking part in the project help you?

- I will listen to everything you want to say

- I cannot promise that taking part will make a difference to your treatment or discharge.

- I hope the project will tell us how to support people in assessment and treatment units better

- I hope you will enjoy talking to me

Might any of the questions upset you?

- You can decide what you want to talk about

- We can stop the interview at any time if you feel upset

- If you are very upset I can arrange for you to speak to someone else

Will I tell anyone else what you have said?

- Everything you tell me is Confidential (Private)

- This means I will not tell anyone else what you have said to me.

- I will only break this rule if you tell me something that makes me worried about the safety of you, or someone else.

- If I am worried, I will talk to the unit Manager so we can keep you safe. I will let you know you if I have to do this.

What will happen if you want to take part?

- If you would like to talk to me a member of staff will help you fill in a consent form

- I will arrange a time to meet you

- If you would like someone with you during the interview that will be ok

- I would like to tape record our interview so I do not forget what you tell me

- I will keep the tape in a safe place and nobody else will be allowed to listen to it

- I will contact the staff member and carer you choose and arrange to talk with them
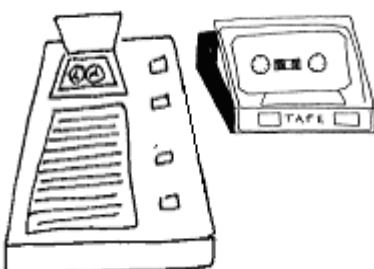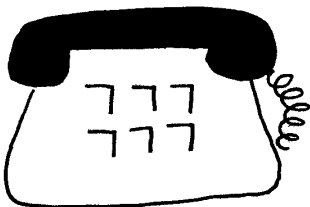
What happens when the research ends?

- When I have finished all the interviews I will write a report about what everyone says.

- I will not put any names in the report

- If you would like to know about the findings of the project I can send you a report.

What if there is a problem?

- If you are unhappy with this project you can talk to your Manager or a member of staff who will help you make a complaint.

What if you have more questions?

- You can contact me or my supervisor, Dr Rosemary Jenkins (Consultant Clinical Psychologist) on 029 2020 6464.

Appendix 10: Staff/Carer Information Sheet

SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

VERSION 2 22/06/2011

STAFF / CARER PARTICIPANT INFORMATION SHEET

The experiences of adults with learning disabilities in specialist inpatient assessment and treatment units.

I would like to invite you to take part in a research study which is being carried out by myself, Hayley Hill (Trainee Clinical Psychologist), under the supervision of Dr Rosemary Jenkins (Consultant Clinical Psychologist) and Professor David Allen (Associate Clinical Director, Learning Disability Services, Abertawe Bro Morgannwg University Health Board).

Before you decide whether to take part it is important for you to understand why the research is being done, and what it would involve for you. Please take time to read the following information carefully. If you want to ask any questions or would like further information then please free to contact me via the address, email or telephone number below.

What is the purpose of this study?

The purpose of the current study is to explore service users' experiences in specialist inpatient assessment and treatment units. The study aims to obtain service users' views, as well as those of staff members and carers who know them well.

Inpatient services are necessary to support adults with learning disabilities who present with significant challenging behaviour and / or mental health problems. However, to date, very little research has been done to find out what service users think and feel about inpatient units. The current study therefore aims to address the lack of research in this area and contribute to a better understanding of service users' experiences.

It is hoped that the findings from this study will enhance the support service users receive in inpatient units, inform staff training and contribute to service/policy development.

Why have I been invited to take part?

You have been invited to take part in this research because you have been identified by _____ as someone who knows them well. They have agreed to take part in this research and have agreed for me to contact you to discuss their experience in the assessment and treatment unit.

You have been invited to take part because you are:
a) A member of staff, employed for at least the last 6 months on the assessment and treatment unit, who has supported _____ during their admission as part of their key work team

or:

b) A family member, or paid carer, who has been involved in supporting
_____ during their admission and for at least 6 months before it.

Do I have to take part?

No, this research study is voluntary. It is entirely up to you if you want to take part or not. If you decide to take part you will be given this information sheet to keep and asked to sign a consent form.

If you decide to take part and then change your mind later, you will be free to withdraw from the study. You will not have to give any explanation and any information you have given up to that point will not be used in the research.

What am I being asked to do?

If you decide to take part in the study you will be asked to sign a consent form and provide the researcher with your contact details. The researcher will then contact you to explain more about the study and to answer any questions you may have. If you are still happy to take part the researcher will arrange a time to meet with you to carry out an interview.

During the interview the researcher will talk to you about _____ experience in the assessment and treatment unit. You will be asked about how you think they have experienced various different aspects of their admission.

The interview will take place at a time and place that is convenient for you and will last between 60-90 minutes. The interview will be audio-taped so that a written record of the interview can be made for the researcher to use in their analysis.

What are the possible advantages of taking part?

It is hoped that participants will welcome the opportunity to contribute to a better understanding of service users' experiences in assessment and treatment units and inform future service development and delivery.

What are the possible disadvantages of taking part?

There are no known risks involved in taking part in this study, however, some participants could find the topic sensitive and issues may arise which cause upset. If this occurred during the interview and you did not wish to continue, the researcher would stop immediately and provide support. It could also be arranged for you to speak with someone independent of the research if you wished (e.g. a qualified Clinical Psychologist). You would be under no obligation to continue: the interview could be rearranged or you could withdraw from the study altogether.

Will my taking part in this study be confidential?
Yes. The researcher follows a strict ethical and professional code of conduct that requires all information obtained remains confidential and anonymous. You will not be able to be identified by anyone other than the researcher. Each of the audio-tapes will be given a

code and stored safely in order to maintain your anonymity. All names will be changed in the written record of your interview and therefore you will not be identifiable. The audio-tapes and written records will be stored in a locked cabinet within the University Health Board, and only the researcher will have access to this data. Once a written record of your interview has been made the audio-tape will be destroyed.

This confidentiality would only be broken if I became aware of malpractice, misconduct or possible risk to you or another person. If this occurs, I will discuss this information with the Assessment and Treatment Unit Manager, or Lead Manager, in accordance with NHS procedures and my professional codes of practice. I will let you know that I am going to do this.

What will happen to the findings of the study?

The results of the study will be written up as a doctoral thesis and submitted as part of my examinations towards a Doctorate in Clinical Psychology. Direct quotations from the interviews will be included in the thesis, but all identifiable information will be removed. Upon completion of the study a summary sheet outlining the main findings will be sent to those participants who have indicated that they would like a copy of the research outcome. It is hoped that the findings from this study will be presented in an academic publication, local service meetings and/or at national conferences.

What if I have a problem with the study?

If you are unhappy with any aspect of this study or have any concerns, please contact the researcher or alternatively Dr Rosemary Jenkins (contact details below). If you remain unhappy and wish to complain formally we will give you contact details of other people who may be able to respond to your concerns.

Who has reviewed this study?

All research carried out by the NHS is reviewed by an independent panel called the Research Ethics Committee. This is to ensure the safety, rights and welfare of anyone who participates in a research project. This study has been reviewed and given favourable opinion by the South East Wales Research Ethics Committee.

Further information

If you have any further questions about taking part in the study or require any more information please do not hesitate to contact me (Hayley Hill) at the Psychology Department on 02920 206464, email me hillh2@cardiff.ac.uk or contact me at the address below, and I will get back to you as soon as possible.

THANK YOU FOR CONSIDERING TAKING PART AND TAKING THE TIME TO READ THIS INFORMATION SHEET
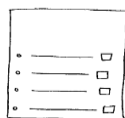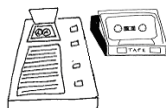
Appendix 11: Service User Consent Form

VERSION 3 22/06/2011

Service User Consent Form

	Yes	No
Have you read (or had read to you) the information sheet (version 4 22/06/2011)?	[ ]	[ ]
Do you understand what you have been told about the project?	[ ]	[ ]
Have you asked all the questions you want?	[ ]	[ ]
Do you understand that you can stop taking part at any time?	[ ]	[ ]
Do you understand that everything you say will be confidential unless Hayley is worried about someone's safety?	[ ]	[ ]
Do you agree to take part in a taped interview?	[ ]	[ ]
Do you agree to the things you say being written up in a report?	[ ]	[ ]
Do you agree to Hayley contacting you to arrange a time and date to meet?	[ ]	[ ]

If you do not want to take part, do not sign your name.

I agree to take part in this project:

_____   _____   _____
Service User's name (printed)   Signature   Date

Contact Number_____

I, the undersigned, confirm that I read through and discussed the information sheet with the participant who has agreed to take part in the study:

_____   _____   _____
Name of person taking consent   Signature   Date
   (printed)

	Yes	No
Do you agree for Hayley to contact and talk to a member of your key work team about your time on the assessment and treatment unit? If yes, who?_____	[ ]	[ ]
Do you agree to the things _____ says being written up in a report?	[ ]	[ ]
Do you agree for Hayley to contact and talk to one of your carers about your time on the assessment and treatment unit? If yes, who?_____	[ ]	[ ]
Do you agree to the things _____ says being written up in a report?	[ ]	[ ]

I agree to the above:

_____   _____   _____
Service User's name (printed)   Signature   Date

_____   _____   _____
Name of person taking consent   Signature   Date
(printed)

Appendix 12: Staff/Carer Consent Form

SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

VERSION 3 22/06/2011

STAFF / CARER CONSENT FORM

Study Title: The experiences of adults with learning disabilities in specialist inpatient assessment and treatment units.

If you decide to take part in this study, all of the information you provide will be kept confidential. You are under no obligation to participate and have the right to withdraw at any time.

Name of researcher: Hayley Hill

	Please initial the boxes if you agree
1. I confirm that I have read and understood the information sheet version 2 22/06/2011 for the above study. I have been given the opportunity to consider the information and have any questions answered adequately.	[ ]
2. I understand that my participation is entirely voluntary. I will be free to withdraw at any point, without giving any explanation, and any data I have given up to that point will not be used for analysis.	[ ]
3. I understand how my confidentiality will be ensured.	[ ]
4. I agree to take part in a taped interview and to this data being included in a report to be submitted by the researcher as part of her doctoral qualification.	[ ]
5. I agree to take part in the above study.	[ ]
6. I would like a summary of the research findings on completion of the study.	**Please circle YES NO**
If you have indicated 'yes' to the above question please provide details of where you would like the summary sent (i.e. email or address): _____	

_____   _____   _____
Participant's name (printed)   Signature   Date

Contact Number_____

_____   _____   _____
Name of person taking consent (printed)   Signature   Date

Appendix 13: Service User Semi-Structured Interview Schedule

VERSION 2 – 23/03/2011
<div align="center">Service User Semi-Structured Interview Schedule</div>

The following questions will provide a framework for the interview. Visual prompts will be used to help service users generate responses where appropriate including: assessment and treatment unit picture, activities, good / bad symbols, helpful / unhelpful symbols, emotions pictures, medication, psychotherapeutic input, behavioural interventions, staff, meetings

Introduction:
Thank you for meeting with me today. I would like to read through the information sheet again to remind you what the project is about and to check you are still happy to take part (read information sheet and sign consent form again)

I would like to talk to you about your time in the assessment and treatment unit. Are you happy for me to ask you some questions about that? Remember, you can say no if you want at any time and we will stop. Is there anything you would like to ask me before we start?

Warm up questions:
- What have you been doing so far today?
- What's your favourite TV programme / sports team / food?
- How do you like to spend your time at home?
- Where do you live?
- Who do you live with?

Core themes and prompts for discussion:

1. The admission process
   Tell me about when you first came to the assessment and treatment unit
   Prompts
   - Why did you come here?
   - What did people tell you about why you came here?
   - What did you think when you first arrived?

2. The assessment and treatment process
   Tell me about the help and treatment you are having
   Prompt
   - What have people done to try and help you get better?
   - Have you been having medication? Why? What do you think about taking this medication?
   - Have people talked to you to try and help you get better?
   - What do people do if you get upset?

   - What do you think about X (specified treatment received)?
   - How do you feel about X?

3. <u>The recovery process</u>
   Do you think you are getting better?
Prompts
   - Why are you getting better?
   - How do you know you are getting better?
   - What feels different now (to when you first came here)?

   - Why do you think you are not getting better?
   - What would help you get better?

4. <u>The discharge process</u>
   What are the plans for when you leave here?
Prompt
   - What do you think about these plans?

5. <u>Service User involvement</u>
   Do staff ask you what you think when decisions are made about your care?
Prompt
   - Do staff ask how you feel about the treatment you have?
   - Have staff asked you what you want to happen when you leave?
   - What would you like staff to ask you about?

6. <u>Environment</u>
   Tell me what the assessment and treatment unit is like
Prompts
   - What do you think about how it looks?
   - Do you have activities to do?
   - What you think about the activities they have?

   - How do you get on with the other service users?

   - How do you get on with the staff?
   - What do they do well?
   - What would you like staff to do differently?

   - Will you miss anything when you leave?
   - How would you change the assessment and treatment unit if you could?

7. <u>Overall experience</u>
   Tell me what you have thought about your time on the assessment and treatment unit.
Prompts
   - What things have been good / helpful?
   - What things have been not good / unhelpful?

   - Is there anything that has made you feel happy?
   - Is there anything that has made you feel upset?
   - Is there anything that has made you feel angry?

Cool down questions:
- Is there anything else you would like to say?
- What are you going to do next? Later?
- Have you got anything planned for the rest of the week/end that you are looking forward to?

State the interview has ended. Thank the service user for taking part and praise them for their contribution, explaining how useful it will be. Verbally re-affirm that the service user is happy for you to use their interview in the research.

Appendix 14: Staff/Carer Semi-Structured Interview Schedule

VERSION 2 – 23/03/2011

Staff / Carer Semi-Structured Interview Schedule

The following questions will provide a framework for the interview.

Introduction:
Thank you for meeting with me today. As outlined in the information sheet, I am doing a research project about the experiences of adults with learning disabilities in assessment and treatment units. _____ (participating service user) identified you as a staff member / carer who has supported them during their time on the assessment and treatment unit and who knows them well enough to comment on their experience. I would therefore like to talk to you about how you think _____ has experienced during their time on the unit. I would like you to think about how they have felt and behaved; what they have thought and what they have understood.

Warm up questions:
Staff / Paid Carers:
- How long have you been supporting adults with learning disabilities?
- How long have you worked with _____?
- What is your role in supporting _____?

Family members:
- What is your relationship with _____?
- What is your role in supporting _____?

Core themes and prompts for discussion:

8. <u>The admission process</u>
    How do you think _____experienced the initial process of being admitted?
    Prompt
    What do you think _____ understood about why he /she was admitted?

9. <u>The assessment and treatment process</u>
    What assessment and treatment has _____ undergone during his/her admission?
    What do you think _____'s experience of this has been?
    Prompt
    What do you think _____ has understood / thought / felt about the assessment and   treatment he/she has received? eg. medication, psychotherapeutic input, behavioural   interventions, positive behavioural support, emotional support or any other therapeutic intervention

10. <u>The recovery process</u>
    What do you think _____ understands about their process of recovery?

11. <u>The discharge process</u>
Could you tell me about _____'s discharge plans.
What do you think _____ thinks about these plans?

12. <u>Service User involvement</u>
How do you think _____ has experienced being involved and included in   decision making during their admission?

13. <u>Environment</u>
How do you think _____ has experienced the environment of the assessment and   treatment unit?
Prompt
What do you think they have thought/felt about the physical environment / activities / other   service users / their relationships with staff?

14. <u>Overall experience</u>
Tell me how you think _____ has experienced his/her admission on the unit.
Prompt
What do you think_____ has experienced positively?
What do you think _____ has experienced negatively?

15. Final comments
Do you have any other thoughts or comments that you think might be important for this   study   or   that   might   help   us   to   understand   _____'s experience?