Mainstream in-patient mental health care for people with learning disabilities: service user and carer experiences

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D.Clin.Psy. thesis (volume 1), 2007

University College London

UMI Number: U591935

UMI

Dissertation Publishing

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Overview

The following thesis is divided into 3 distinct parts. Firstly, the literature review is meant to set the scene and provide an overall examination of the experience of being a mental health inpatient. It specifically focuses on the experience of adults in mainstream settings and looks at the main research evidence across a number of different domains. These include key influential studies, the research on coercion in the inpatient setting and finally an analysis of the experiences of treatment.

The empirical paper presents the main study which examines the experiences of people with learning disabilities and their carers in mainstream psychiatric settings. It begins by summarising the main findings within both the general adult population and for people with learning disabilities and provides a rationale for the study. A presentation of the research method follows along with the results which outline the themes derived form the analysis and the relevant quotes. This is followed by a discussion of the findings.

Finally, a critical appraisal of the research process is presented. This focuses on methodological considerations, in particular recruitment and ethical issues.

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Acknowledgements

Part 1: Literature Review

Adult Service User Views and Experiences of Mainstream Inpatient Mental Health Care

Abstract

Government guidelines stress the importance of service user views when assessing and developing quality healthcare provision. This review examines what is known about the experience of being admitted and staying on a mainstream psychiatric ward from the perspective of the patient. The review firstly provides a context to the main body of literature by discussing relevant factors such as stigma and ethnicity. In depth examination of the three main areas relevant to the experience of service users is then discussed. This includes overall key research, the studies on coercion and those focussing on treatments. Both quantitative and qualitative studies are examined along with relevant methodological issues. This review highlights the diverse nature of user views as well as how important it is to listen to people on the receiving end of help.

Introduction

The specific aim of this review is to answer the question "what is it like to be a mental health inpatient?" The broader goal is to identify and examine the important domains of experience and how these relate back to the service user. I have attempted to identify the key research published in the last 20 years that addressed mental health inpatient views and experiences which in some cases also includes the views of staff and carers. I have focused on studies that deal solely with adult populations (age 18 to 65) in mainstream services. This review therefore excludes research conducted in forensic and private settings along with the experiences of older adults, people with learning disabilities and adolescents in specialist services. This review is not restricted to UK studies but incorporates research conducted in Europe, North America and Australasia, in part to address a limited research base, but also to widen the generalisability of findings.

The electronic databases searched were: Ovid Medline; Ovid PsycInfo; Google Scholar; Ingenta Connect and Blackwell Synergy. The inclusion criteria for publications to be considered in the review were:

1. Studies looking at the experience or views of service users in inpatient mental health settings

2. Both quantitative and qualitative studies

3. Published, in English, since 1985

4. Excluding studies concerned with older adults, adolescents, people with learning disabilities or research conducted in non mainstream settings.

The following general search terms were employed:

1. Service AND User (title)

2. Inpatient AND Experience (title)

3. User AND View (title)

The following Google Scholar search terms were employed:

1. allintitle: Service user views

2. allintitle: Mental health inpatient

3. allintitle: Inpatient satisfaction

Hand searches of several journal titles for relevant studies include the British Journal of Psychiatry 2000-2007 and Clinical Psychology (Monthly DCP publication), 1990-2007.

The review itself is split into four sections and follows a logic of increasing specificity. The first section provides a broad context and rationale for service user research focusing on issues such as stigma and ethnicity. The second section deals with the overall inpatient experience by examining key influential studies and the main body of research. It also incorporates relevant research on the views of staff and carers. The third section looks more specifically at the notion of coercion and examines the studies conducted in this area and the final section examines patient experiences of particular treatments such as medication and ECT.

Section 1: Service Users in Context

This section provides a rationale for conducting service user research and discusses wider issues relevant to the inpatient experience. For example, both ethnicity and stigma are examined as well as the different perspectives encountered both within and between services and service users.

The views of Service Users

The service user's perspective has been granted a level of importance in part due to the pressure put on health care providers to demonstrate that they have incorporated the views of patients when planning and evaluating services. This position is founded on a political discourse that publicly supported services should be accountable both to those who fund them and those they treat (Department of Health, 1999; Edwards, 2000). Another perhaps more pressing reason is the increasing awareness of how distressing being a mental health patient can be, an experience often characterised by social exclusion (British Psychological Society, 2000; Perkins, 2001; Rogers & Pilgrim, 1993). In other words, in the context of their vulnerability and inarticulateness there is an important moral reason for representation.

Those treated within the mental health system are often constrained to live lives that are shaped by stigma, isolation, homelessness and denial of rights (Kelly, 2005). Inpatients are often in an even worse position, with an existence characterised by all of the above along with difficulties associated with confinement inside a rule bound institution. An important facet to this experience is the significant difference between professional and lay opinion regarding the origins of mental distress. A large proportion of psychiatric medical training uses biological and genetic explanatory models, which according to the evidence form a minority lay view

(Jorm, 2000). This immediately sets up a dissonance between mental health staff and their patients.

Related to this is whether services tend to respect or reject user opinion. Perkins (2001) argues that there is an assumption that people with mental health problems have a diminished ability to define their own needs and wants. This implies that the views of other stakeholders would tend to take precedence. For example, a recent study suggested that there were high levels of agreement between health teams and patients as to what constituted a need (Hansen, Hatling, Lidal & Ruud, 2004). However, in situations of disagreement like provision of medication and deprivation of liberty within hospitals, health workers tended to act on their own volition rather than listening to patients' views.

We also find evidence of conflicting viewpoints in the way professionals use the importance of insight. Inpatient treatment is often centred on the concept of a person having insight into their condition despite evidence showing that patients do not see this as relevant (Perkins, 2001). It has been suggested that in an everyday assessment of insight, what is of interest is whether the explanation of the individual in focus accords with professional opinion (Hamilton & Roper, 2006). This might emphasise feelings of disempowerment in an inpatient context as the patient's own explanatory model is at best superseded, and at worst pathologised by healthcare professionals (Hamilton & Roper, 2006).

Stigmatisation

Stigma is a negative attribute that marks an individual or group as being inferior (Goffman, 1963). This often characterises the experience of having a mental health problem and the person with a stigma is seen by others as 'not normal' (Goffman, 1963). On the basis of this assumption, other people can exercise acts of

discrimination through which they effectively, if often unthinkingly, reduce their life chances. Furthermore, a defensive response by a stigmatised person to their situation is likely to be seen as a direct expression of their deficit or 'illness'. It follows that other people such as the staff on an inpatient ward might view both defect (psychological problem) and response (complaint) as a justification for psychiatric treatment (Goffman, 1963).

Stigmatisation is starkly demonstrated in a study which compared the experience of gift giving and disclosure in physical and mental health settings (Bromley & Cunningham, 2004). Those admitted for mental health problems received half the number of cards from friends and relatives. Gifts were also more practical with far fewer luxury goods like flowers and chocolates. Disclosure to friends and family about the admission was also significantly lower in the mental health inpatient group (Bromley & Cunningham, 2004). Stigma is therefore reflected in the secrecy surrounding hospital admission and the way in which the person is likely to be treated by their friends and relatives.

Ethnicity: Black African and Caribbean Inpatients

The inpatient experience seems to differ for ethnic populations. In particular, black African and Caribbean service users are over-represented within psychiatric institutions above all other ethnic groups (Sainsbury Centre for Mental Health, 2002). Since they are arguably one of the most disenfranchised groups within UK society as well as the NHS (Sainsbury Centre for Mental Health, 2002), this review will use them as a case example.

In a general review of the literature as well as through localised research projects that involved focus groups and semi structured interviews with patients and staff, the Sainsbury Centre for Mental Health (2002) examined the experience of

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black mental health service users. Accounts of inpatient mental health are often characterised by fear and apprehension (Sainsbury Centre for Mental Health, 2002). Patients reported that staff failed to negotiate with them during difficult times and often used control and restraint in an arbitrary fashion. Furthermore, the relationship between staff and black patients in particular was unsatisfactory and distant (Sainsbury Centre for Mental Health, 2002). Medication was also a chief concern for black inpatients, especially the lack of alternative treatments, side effects and general absence of information. The review also concluded that many NHS services did not know how many black people were detained in their locality or how many were in acute settings in order to confirm an over representation bias. These knowledge gaps in themselves regarding ethnicity of patients suggest a lack of concern for the issue.

Black people are also more likely to have a diagnosis of schizophrenia and for diagnoses themselves to be more inconsistent across time (Pierre, 2000). They are most likely to be detained on locked psychiatric wards and be in receipt of higher doses of medication (Sainsbury Centre for Mental Health, 2002; Wilson & Francis, 1997). Furthermore, they are also more likely to receive ECT and less likely to be offered talking treatments (Wilson & Francis, 1997). Such figures support the notion that these patients are likely to endure what academic and government sources describe as a form of institutional racism (DOH, 2005; Wilson & Francis, 1997). A study exploring this issue found that the majority of those interviewed felt they had encountered overt racism within the hospital system. This took the form of not being understood or dismissed by staff, being given different treatments to other patients and being seen according to stereotypes, for example black men as violent (Secker & Harding, 2002). On the whole, the study showed that trust between staff and black patients was more adversely affected than with other patient populations.

Different Types of Service User

Users of mental health services can be conceptualised as either passive recipients, consumers who choose their treatments or survivors who have resisted the mental health system (Speed, 2006). An interesting paper by Speed (2006) looks at each of these three discourses through case study examples. This is highly relevant as inpatients are likely to see themselves in one of the three roles highlighted below:

As a Patient	• A Passive stance implies an active support of biomedical perspective, absolving person of blame for their situation.
As a Consumer	• A negotiated stance that accepts treatment through consultation. Also willing to accept biomedical model.
As a Survivor	• A dissenting stance to treatment which challenges and rejects the other two positions. Proposes alternative aetiologies to biomedical understanding.

The study emphasises the importance of the different levels of agency that each discourse affords the user. For example, the intrinsic passivity of the 'patient' compared to the negotiated stance of the 'consumer' or the active resistance and dissent of the 'survivor' (Speed, 2006). The researcher also acknowledges the effect of these stances on what a person is able to talk about, in other words the 'patient' may be more internally constrained than the 'consumer' or 'survivor' when self reporting (Speed, 2006).

Section 2: The General Inpatient Experience

This section examines in detail some of the influential large scale research studies into the experience of being a mental health inpatient. It also provides an analysis of the overall research findings for the area including the perspectives of carers and staff. However, it excludes studies whose focus is on specific aspects of an admission such as coercion and treatment as these will be discussed in later sections. A Summary of the main studies are shown in Table 1.

The Rogers and Pilgrim (1993) study

A major study commissioned by MIND was one of the first significant pieces of research that looked holistically at the experience of being a mental health inpatient. Both qualitative and quantitative measures were administered to a sample of UK service users who had had at least one inpatient admission (n=516). Sixty five participants had at least 3 months unbroken stay on an acute psychiatric ward and approximately half the sample had been admitted at least four times (Rogers & Pilgrim, 1993).

Overall, patients had mixed feelings about ECT and preferred medication in the context of fewer side effects. However, the researchers felt that the quantitative data underestimated patients' dissatisfaction with major tranquillisers. For example, relatively few qualitative statements were supportive and many of those that rated drugs as beneficial made statements that seemed to mask negativity and ambivalence (Rogers & Pilgrim, 1993). The experience of occupational therapy was significantly dependent on age, with older people (>56) more likely to view it as positive. Sixty percent of the sample received talking therapy, which was reported most favourably compared to other treatments.

Table 1. A Summary of the main studies examining inpatient views

Author	Sample Type	Location	Sample Size	Data Collection
Chafetz (1996)	Convenience sample of mental health patients in both in and out patient settings.	USA	N=43	Life Chart Interview adapted from the Vermont Longitudinal Questionnaire
Cleary, Hunt, Walter & Freeman (2006)	Group 1: Patients discharged from acute mental health services in a major city Group 2: Their carers	Australia	Patients N=200; Carers N=35	Camberwell Assessment of Need (CANSAS); Involvement Evaluation Questionnaire (IEQ).
Edwards (2000)	Group 1: Users of mental health services; Group 2: Nurses in training	UK	Qualitative: Patients N=28; Nurses N=44. Quantitative: Patients N=200; Nurses N=200	Semi-structured focus groups; questionnaires based on outcome of focus groups (all measures designed by researcher)
Goodwin, Holmes, Newnes & Waltho (1999)	Inpatients on acute and rehabilitation wards in a rural psychiatric hospital.	UK	N=104	Modified version of Survey Satisfaction Questionnaire (SSQ); Semi-structured interview. Data gathered longitudinally over 4 years
McKenzie (2006)	Group 1: Patients from an outpatient psychosis service; Group 2: Their carers	UK	Patients N=12; Carers N=12	Self report questionnaire and semi-structured interview designed by the researcher

Table 1 Contd. A Summary of the main studies examining inpatient views

Author	Sample Type	Location	Sample Size	Data Collection
Koivisto, Janhonen & Vaisanen (2003)	Voluntary inpatients in a psychiatry clinic	Finland	N=9	Semi-structured interview
Kuosmanen, Hatonen, Jyrkinen, Katajisto & Valimaki (2006)	Patients discharged from a psychiatric hospital over a 1 year period	Finland	N=313	Self rated patient satisfaction questionnaire (SPRI)
Morrison (1999)	Random sample of all those admitted to a psychiatric hospital over a 6 year period	UK	N=34	Post discharge postal survey: Hospital Anxiety and Depression Scale (HADS); Impact of Events Scale (IES); Hospital Experiences Questionnaire (HEQ)
Myers, Leahy, Shoeb & Ryder (1990)	Inpatients admitted for longer than 5 days from 4 psychiatric hospitals (not including severe cases)	UK	N=254	54 item 5 point response scale questionnaire devised by the researchers
Pejlert, Asplund & Norberg (1995)	Inpatients diagnosed with schizophrenia	Norway	N=10	Narrative interviews based on 3 key themes
Rogers & Pilgrim (1993)	Nationwide convenience sample of psychiatric patients with at least 1 inpatient admission	UK	N=516	Questionnaire and semi-structured interview designed and piloted by the researchers

Table 1 Contd. A Summary of the main studies examining inpatient views

Author	Sample Type	Location	Sample Size	Data Collection
Speed (2006)	Mental health service users with a history of admissions and drawn from either patient groups or consumer or survivor organisations	UK	N=12	Semi-structured interview
Wood & Pistrang (2004)	Group 1: Inpatients on acute psychiatric ward; Group 2: Staff on same ward	UK	Patients N=9; Staff N=7	Semi-structured interview

Satisfaction also increased as a function of length of treatment as well as in the amount of information given to the patient regarding the model of talking therapy (Rogers & Pilgrim, 1993).

To summarise, this research indicated that patients felt rather ambivalent with regards to their inpatient experience. However, there seems to be a general consensus that treatments are preferred in the context of good relationships with staff (Rogers & Pilgrim, 1993). A key feature to arise from the data is patients' dislike in being objectified and treated impersonally by mental health staff. The authors link this to underlying factors such as biomedicine's failure to recognise the importance of the subjective and not taking seriously notions of personal growth. They suggest that treatments perceived as non-medical such as talking therapy are endorsed more as a result (Rogers & Pilgrim, 1993).

The Goodwin, Holmes, Newnes and Waltho (1999) Study

Another key influential study is a qualitative analysis of inpatient service users (n=104) conducted over a four-year period in the UK (Goodwin et al.,1999). A semi structured interview schedule was used and analysed through a combination of grounded theory and content analysis. The following emerged (key themes highlighted in italics):

- Patients often referred to the *tangible environment* such as the atmosphere or facilities. The majority of patients felt that food was of poor quality.

- The majority of patients talked about issues surrounding *power and control* and often felt coerced as an inpatient.

- Patients spoke of the *need to feel listened to* and the positive experience surrounding talking treatments but felt that access was limited.

- Many patients reported feeling infantilised or hurt by staff that failed to treat them with *respect*.

- Participants reported that the sharing of *information* was a rarity

- The majority of patients made appreciative comments about *staff* and expressed a sense of being cared for.

- Many patients were positive about the opportunity to *relax or be active* and put this down to having an occupational therapy department.

- Most patients were positive about *practical help* provided by staff in relation to things like finances or housing.

As the study is longitudinal the researchers concluded that the qualitative data did not vary over the four-year period. This suggests that the inpatient experience is relatively stable despite changes in staff and NHS policies (Goodwin et al., 1999). However, the authors point out that the study was likely to be influenced by their own beliefs about the mental health system as well as the inherent power disparity between researcher and patient. On the one hand this is an inherent feature of qualitative research in general but does suggest that this study is at best a partial reflection of service user views.

Other Research

A study that utilised a self selected sample (n=43) looked at the overall experience of mental health problems through a qualitative life chart interview (Chafetz, 1996). Participants spoke of the significance of coming into the system that often involved radical changes to their personal identities, in other words a transition from being labelled as 'normal' to one who is 'mentally ill' (Chafetz,

1996). They also discussed the importance of environmental factors such as housing, finances and non-pharmacological methods of symptom management. Participants also valued the role of social support such as family, friends and close professionals. Overall, participants acknowledged the central role of medication in the management of their problems but also to individual learning and choice making (Chafetz, 1996).

A study that examined the needs of inpatients and whether these were being met (Cleary, Hunt, Walter & Freeman, 2006) used a large sample size (n=200) and had a high response rate (78%). Participants filled out several self-report questionnaires on discharge from their respective wards. Overall, patients with affective disorders had more unmet needs than those with other diagnoses, especially the schizophrenic group (Cleary et al., 2006). The unmet needs included food, physical activity, psychological distress and human company.

A small phenomenological qualitative study conducted in Finland looked at the experiences of psychosis in the context of an inpatient ward. Key findings were participants' sense that they had little control over their emotional lives and that they had lost confidence in themselves due to experiences of poor judgement and an inability to relate to others (Koivisto, Janhonen & Vaisanen, 2003). They also located the causes of their psychoses in past experiences outside of hospital. A similar study (Pejlert, Asplund & Norberg, 1995) corroborated these findings and found that inpatient narratives often involved references to feeling fatigued and a longing for pre-illness days. The former study (Koivisto et al., 2003) looked at the process of admission and many participant accounts viewed this as inevitable but shameful and frightening at the same time.

A large quantitative study (n=313) conducted in Finland using a self-report measure looked at patient satisfaction with psychiatric inpatient care (Kuosmanen, Hatonen, Jyrkinen, Katajisto & Valimaki, 2006). Overall, patients reported generally

good levels of satisfaction with their care that is consistent with other self-report studies. However, they reported lower satisfaction with restrictions and compulsory care during their hospital stay. Information access was also criticised, again in line with similar research (e.g. Goodwin et al., 1999). Staff-patient interaction was the area of greatest satisfaction but interestingly, both young people and women found this relationship less satisfying than older patients (Kuosmanen et al., 2006).

A similar study conducted in the UK by Myers, Leahy, Shoeb and Ryder (1990) examined 254 inpatients' levels of satisfaction across 4 hospitals. The study overall suggested that patients were satisfied with inpatient care, in particular they felt accepted as people and experienced their identities as preserved. However, many complained about the material provision on the wards such as access to finances and physical attributes of the building as well as highlighting issues of concern such as being harassed by other patients for money and cigarettes (Myers et al., 1990). The study goes into some detail regarding methodology issues and draws attention to ecological factors like the inherent complexity of inpatient life and the impoverished lives of many patients outside of the hospital setting. A relatively better quality of life in hospital may have affected this and similar studies by positively skewing reported satisfaction levels (Myers et al., 1990).

Service Users and Carers

In a survey administered to both patients (n=41) and carers (n=41) about their experience of mental health services, a number of points relevant to inpatient admissions emerged (Mckenzie, 2006). Many patients had found it difficult to access help in the first place and in some cases only received help when acutely unwell. Also, the majority of patient respondents were offered medication whilst only a handful (8%) had access to talking therapy. The research also found that

patients found talking to be the most helpful aspect of their treatment (Mckenzie, 2006). The greatest concern amongst the carer group was the lack of patient access to talking treatments and the ability of services to provide adequate care pathways alongside the admission (Mckenzie, 2006). On the whole this study reflects previous research and despite the low response rate (29%), it is one of a few studies that attempt to incorporate the views of carers.

An interesting dimension of the Cleary et al. (2006) study is a focus on carer perceptions. The results indicated that patients were not fully aware of how burdened their carers felt and that carers often did not share the same concerns as patients. For example, they tended to worry in regard to future competency in every day activities and poor social prospects post discharge (Cleary et al., 2006). However, the study is limited in its generalisability due to a low carer response rate and a large number of statistical comparisons in the analysis. Another study by Hoge, Lidz, Eisenberg, Monahan, Bennett, Gardner, Mulvey and Roth (1998) which looked specifically at the experience of coercion incorporates a carer's perspective and will be discussed in section 3 of this review.

Service Users and Staff

A study by Edwards (2000) looked at inpatient user views in the context of relationships with nursing staff. The research used both qualitative focus groups (patients n=28 and student nurses n=44) and quantitative questionnaire data (patients n=200 and student nurses n=200). Patients wanted to be listened to and given greater independence as well as for staff to spend more time with them and to manage aggression on the ward (Edwards, 2000). Patients also expressed dissatisfaction with mental health diagnoses and saw the role that nurses fill to be primarily administrative, dispensing medication and performing custodial duties (Edwards,

2000). Patients also viewed group therapy as unhelpful and a diversion from more important issues. Interestingly, the data suggests a prevailing concern of student nurses that they would be pressured later in their careers into becoming part of a culture that is not in the best interest of patients (Edwards, 2000).

A qualitative study by Wood and Pistrang (2004) sought to examine both staff and patients experience of mental health wards with a particular focus on feelings of safety and threat. Patient accounts (n=9) were characterised by a sense of vulnerability and helplessness as well as implying that assault and harassment were commonplace. They also repeatedly experienced staff as unavailable and impotent when asked to mediate problems on the ward (Wood & Pistrang, 2004). Interestingly, when asked to imagine what an admission would be like for a patient, staff (n=7) thought it would be terrifying. Although the study is an informative qualitative contrast between staff and patient views, it is limited by a small self-selected sample, taken from one inner city location.

Section 3: Coercion

A significant proportion of the literature focuses more specifically on the coercive nature of an admission. For example, the process of being sectioned or the deprivation of liberty whilst on a ward. This section examines the complex notion of coercion as presented in the literature and presents an analysis of the main research studies in the field.

Defining Coercion

Levels of coercion in mental health services have been the focus for many researchers due to its particular relevance for inpatients. Coercion is essentially defined as the use of persuasion, inducements, threats or force to compel or restrain without regard to individual wishes or desires (Collins, 1989; McKenna, Simpson & Laidlaw, 1999). Some authors also divide the term into coercive treatments that are designed to cure or treat regardless of a person's level of resistance, and coercive measures that include the use of techniques like seclusion and restraint (Kaltiala-Heino, Korkeila, Tuohimäki, Tuori & Lehtinen et al., 2000).

Some researchers such as Monahan, Hoge, Lidz, Roth, Bennett, Gardner and Mulvey (1995) in a review of the coercion literature have drawn attention to the concept of quasi-coercion. This is where a patient may be explicitly coerced to make a voluntary admission as a way of avoiding enforced detention. This has confounding implications for much research that uses the voluntary-involuntary admission dichotomy. The same authors also argue that many mental health professionals believe that in the absence of coercion, patients will not receive needed care (Monahan et al., 1995). This implies that staff in inpatient services may actually use coercive techniques simply because they feel it inevitable and necessary.

Enforced Detention

Despite the difficulty of using voluntary-involuntary criteria as a clear-cut research classification, there is some evidence of distinct psychological consequences that result from involuntary detention. For example, when a person enters hospital under a section of the mental health act, they are less likely to view their treatment as helpful (Greenwood, Key, Burns, Bristow & Sedgwick, 1999). Also, a psychiatric admission is likely to be associated with pervasive distress and a number of patients later show symptoms congruent with post-traumatic stress disorder (Morrison, Bowe, Larkin & Nothard, 1999). In other words, almost half the total sample of thirty four former inpatients displayed PTSD symptoms subsequent to admission (Morrison et al., 1999). However, these findings are limited by a very low response rate (13%) and a reliance on self report measures.

Authors have drawn attention to the relationship between coercive aspects of a mental health inpatient admission and psychological theories of social cognition (Monahan et al., 1995). The absence of perceived control or freedom has been found to elicit a number of psychological consequences such as 'reactance' (Brehm & Brehm, 1981), when the perception of freedom has been undermined. This results in anger toward the source of the restriction of freedom. Helplessness (Seligman, 1975) is another psychological reaction to a loss of perceived control. Essentially the opposite of reactance, helplessness engenders depression, anxiety, and the cessation of any personal efforts to alleviate an aversive situation. Importantly, when helplessness results from unsuccessful attempts to change a stressful environment such as on an inpatient ward, it can lead to "learned helplessness," in which experiences with one uncontrollable environment generalise to new environments (Seligman, 1975).

Of note, the nature of mental health problems themselves may make patients feel more coerced and undermine the benefit of an admission. For example, depressed people are more likely to attribute negative events to internal causes (Beck, 1970). If being sectioned is often experienced as coercive and unpleasant as the literature suggests, then the person may associate this experience with some aspect of their own personality (Ross, 2003). Furthermore, a paranoid person is more likely to attribute negative events externally. In particular, they may locate the causes of any unpleasantness with other people and so become more blaming and mistrustful of staff involved in their care (Ross, 2003).

Coercion Research

There have been a number of studies that have specifically looked at the effect of coercive practices on the experience of inpatients. Please see Table 2 for a summary of the main studies. Firstly, a North American qualitative study by Pescosolido, Gardner and Lubell (1998) looked at patient reports of first major entry into care with accounts divided into 3 broad categories: seeking help, muddling through (neither seeking or resisting treatment) and coercion. Less than half the sample of 109 participants had willingly sought help whilst 23% claimed to have been explicitly coerced into treatment. This implies that a significant proportion of those admitted will have either actively resisted care provision or let circumstances dictate their admission. An interesting suggestion from this research is that clinical outcome may be associated with positive patient accounts of entry into treatment (Pescosodilo et al., 1998).

Table 2. A Summary of studies examining inpatient views on coercion

Author	Sample Type	Location	Sample Size	Data Collection
Bindman, Reid, Szmukler, Tiller, Thornicroft & Leese (2005)	Patients admitted to an inner city psychiatric hospital	UK	N=100	The Admission Experience Interview (AEI); The Admission Experience Schedule (AES)
Hoge, Lidz, Eisenberg, Monahan, Bennett, Gardner, Mulvey & Roth (1998)	Group 1: Newly admitted psychiatric patients; group 2: Patient family members; group 3: The admitting clinician	USA	Patients N=433; Family N=210; Clinicians N=372	The Admission Experience Interview (AEI)
Kaltiala-Heino, Korkeila, Tuohimäki, Tuori & Lehtinen (2000)	All working age civil admissions to psychiatric hospitals in a specific geographical region over a 6 month period	Finland	N=1,543	Retrospective chart review on use of coercive treatments gathered via a structured schedule
McKenna, Simpson & Laidlaw (1999)	Group 1: Voluntary patients admitted to acute inpatient services; group 2: Involuntary patients	New Zealand	Voluntary N=69; involuntary N=69	The Admission Experience Schedule (AES)
Olofsson & Jacobsson (2001)	Involuntarily hospitalised psychiatric patients	Sweden	N=18	Unspecified qualitative methodology

Table 2 Contd. A Summary of studies examining inpatient views on coercion

Author	Sample Type	Location	Sample Size	Data Collection
Pescosolido, Gardner & Lubell (1998)	Patients making first contact with mental health services and diagnosed with a severe and enduring mental illness	USA	N=109	One to one interviews and self report measures developed by the researchers
Poulsen (1999)	Group 1: Voluntary psychiatric inpatients; group 2: Involuntary psychiatric inpatients; group 3: Patients who were involuntarily detained after an initial voluntary stay	Sweden	Group 1 N=48; Group 2 N=47; Group 3 N=48.	The Admission Experience Interview (AEI); Visual Analogue Scale (VAS)

A UK study aiming to investigate predictors of perceived coercion in an inpatient sample (n=100) found that compulsory hospital admission was strongly associated with perceived levels of coercion (Bindman, Reid, Szmukler, Tiller, Thornicroft & Leese 2005). Furthermore, a third of all voluntary patients felt they were also highly coerced with two thirds uncertain whether they had the right to leave hospital. Overall, perceived levels of coercion were high amongst inpatient populations, especially among ethnic minority groups. For example, 61% of non-white inpatients perceived coercion to be high as opposed to 40% of white inpatients (Bindman et al., 2005).

Hoge et al. (1998) state the importance of recognising coercive practices within the mental health system. For example, a person's legal status is often misleading in that many voluntary patients feel they have no choice in their treatment (Hoge et al., 1998). This study used a semi-structured interview methodology to examine patients' (n=433), carers' (n=210) and clinicians' (n=363) views on the level of coercion associated with a mental health inpatient admission. Patients reported a number of adverse consequences that includes a greater reluctance on the part of coerced patients to seek psychiatric care in the future and non-compliance with recommended care once the coercion is lifted (Hoge et al., 1998). Furthermore, family members often had difficulty accepting that they themselves have been part of the coercive process and that their relationships with the patient have been effected (Hoge at al., 1998). Patients' accounts also noted less procedural justice in the admissions process than either their family members or clinicians which may serve to exacerbate feelings of alienation.

A questionnaire study (n=138) conducted in New Zealand found a similar correlation between legal status and perceived levels of coercion as well as the importance of procedural justice for inpatients (McKenna et al., 1999). The study

also looked at different types of coercion and found significant differences between patient groups; in particular involuntary admitted patients reported use of techniques such as threats and force whilst those admitted informally did not seem to experience these (McKenna et al., 1999). It can be difficult to interpret studies like this as the legal status of a patient is hard to define, for example a patient's status may change throughout the course of treatment or voluntary admission may actually mean 'persuaded', especially in the case of vulnerable adults or children (Monahan et al., 1995). This again serves to blur the boundary between voluntary-involuntary admissions as discussed earlier.

A retrospective case note review of 1,500 Finnish inpatients conducted by Kaltiala-Heino et al. (2000) examined the extent of coercion in psychiatric inpatient treatment. The study found that around 32% of patients experienced some form of coercion, the most common being restrictions on leaving the ward. Mechanical restraints were used with 10% of the patients and 8% were subjected to enforced medication (Kaltiala-Heino et al., 2000). Although these results emphasise the importance of coercion for the inpatient experience, it is probable that the study underestimated the prevalence of coercive techniques, due to its reliance on official records in case notes.

A qualitative study by Olofsson and Jacobsson (2001) focused on the impact of coercion through narrative interviews (n=18). Patients felt that not being involved in their own care, receiving treatments that appear meaningless and being viewed as in some way inferior were significant contributing factors to a bad hospital experience. The authors concluded that overall, the experience of admission was predominantly negative and exacerbated the stigma of being a mental health inpatient (Olofsson & Jacobsson, 2001). A Danish study (Poulsen, 1999) that measured perceived levels of coercion through the use of semi-structured interviews (n=143)

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reported similar findings. Of note, even voluntary patients who received no limitations with regard to personal liberty experienced care on the inpatient ward as coercive (Poulsen, 1999).

Section 4: Inpatient Treatments

This section examines studies relating specifically to the experience of hospital based treatments for mental health inpatients. It focuses mainly on medication since this is the most comprehensively researched and commonly administered treatment. The section also examines patient experiences of ECT and physical restraint. Analysis of talking therapies has been omitted since they are not commonly administered and there are no specific published studies of note.

Medication

Table 3 summarises the main body of this research. Traditional psychiatric drugs are the most common forms of help offered to people with psychotic experiences (BPS, 2000) and therefore warrant discussion in their own right. Up to a third of all patients do not respond well to antipsychotic medication and side effects are often severe and at times fatal (Day, Bentall, Roberts, Randall, Rogers, Cattell, Healy, Rae & Power, 2005). Non-adherence is also common, with up to 50% of people choosing not to continue with their pharmaceutical regimes post admission (Day et al., 2005). Against this backdrop, recent research has found that the most favourable conditions for viewing drug treatment positively and encouraging adherence include a lack of coercion during admission, a positive relationship with the prescriber, involvement of the patient in treatment decisions, and a medication regimen that minimizes adverse side effects (Day et al., 2005).

Table 3. A Summary of studies examining inpatient views on psychiatric medication

Author	Sample Type	Location	Sample Size	Data Collection
Baker, Lovell, Easton & Harris (2006)	Convenience sample of mental health inpatients	UK	N=25	Semi-structured interview with questions devised by a multi-disciplinary team
Day, Bentall, Roberts, Randall, Rogers, Cattell, Healy, Rae & Power (2005)	Patients meeting DSM-IV criteria for schizophrenia or schizoaffective disorder on admission	UK	N=228	Semi-structured interviews and self report questionnaires
Gray, Rofail, Allen & Newey (2005)	Mental health in and outpatients currently taking antipsychotic medication	UK	N=69	Questionnaire developed by the researchers and based on previous measures.
Haglund, Von Knorring & Von Essen (2003)	Group 1: Inpatients on locked wards who had been forcibly medicated; group 2: Staff on the same wards who had been involved with the enforcement	Sweden	Patients N=11; Staff N=8	Semi-structured interview
Harper (1998)	Both users of psychiatric services and mental health professionals (GP's, Psychiatrists and CPN's)	UK	Patients N=9; Staff N=12	Discourse analysis (social constructionist approach)

Table 3 Contd. A Summary of studies examining inpatient views on psychiatric
medication

Author	Sample Type	Location	Sample Size	Data Collection
Muller, Schloesser, Kapp-Steen, Schanz & Benkert (2000)	Inpatients admitted to a psychiatric hospital	Germany	N=135	Unspecified self report questionnaire

Medication Satisfaction

A UK study by Gray, Rofail, Allen and Newey (2005) administered a self report questionnaire investigating satisfaction with medication to a sample of inpatients (n=69). The results were generally positive with around 68% of patients finding their medication helpful. However, patients did not feel involved in treatment decisions and stated they took medication because they were told to. Patients also reported that they had not been given written information about their treatment or warned about side effects, and that alternative non-pharmacological interventions had not been offered to them (Gray et al., 2005). A response rate of 39% meant that a large majority of patients chose not to take part, undermining the reliability of this study.

A similar self report study administered in Germany had a larger sample size (n=135) and a better response rate (49%) and corroborated that patients were generally satisfied with their medication regimes (Muller, Schloesser, Kapp-Steen, Schanz & Benkert, 2000). However, the researchers also measured satisfaction in other areas of inpatient treatment and found medication to be rated relatively low compared to interventions such as talking therapies and occupational therapy (Muller et al., 2000). This suggests that self report studies which ask solely about medication may overestimate patients' satisfaction with medication.

Medication Failure

A small qualitative study that focused on staff and service user accounts of medication (staff n=12; patient n=9) concluded that professionals often used reasons like "the patient is a non responder" or "the patient is chronic" to account for medication not working for some people (Harper, 1998). The implication here is an emphasis on the endurance or permanence of problems with some inpatients being

viewed as difficult to treat or unlikely to recover. Harper (1998) concludes that overall, the use of chronicity or permanence in explaining a failure in the effectiveness of drug therapy removes the impetus and responsibility of stakeholders in finding more effective alternative treatments.

PRN Medication

The experience of being administered as needed (PRN) medication on an inpatient mental health ward has been investigated by researchers in the UK. Baker, Lovell, Easton and Harris (2006) asked twenty five inpatients about their treatment experiences using semi-structured interviews. The majority (86%) felt that PRN was helpful, stressing its flexibility, availability and calming effects (Baker et al., 2006). Accounts stressed that patients felt more in control of their symptoms and empowered by deciding dosage and timing of extra medication. However, patients generally felt confused about the process and system of PRN and were often embarrassed and angry when staff refused to supply requested medication (Baker et al., 2006). The study also found that over half of participants felt they had not been provided with adequate information regarding their medication regime and that patients generally felt unsupported in using alternatives to PRN such as talking therapy or recreational activities (Baker et al., 2006). The limitations of this study include a small sample size and questionable generalisability of the findings to other settings.

Forced Medication

A small Swedish qualitative study used semi structured interviews and content analysis to examine the experience of being forcibly medicated from both the nurse and the inpatient perspective (n=11 and n=8 respectively). Importantly, only a

third of patients retrospectively thought it was a good idea whilst the rest felt it had been of no help at all (Haglund, Von Knorring & Von Essen, 2003). This was in direct contrast to all the nurses who felt medication had a positive effect. Furthermore, the study found that whilst all patients gave several alternatives to being medicated, such as more dialogue with staff, clearer explanations of their condition or just waiting for a short time, the nurses could not name any alternatives to enforcing medication (Haglund et al., 2003). Although the study has a small sample size and was conducted on a single ward, the researchers made efforts to ensure credibility of data interpretation by using experienced interviewers who were uninvolved with the hospital (Haglund et al., 2003).

ECT

Another dimension of the mental health inpatient experience is the use of electro convulsive therapy (ECT), in particular for those with severe depression. Approximately 11,000 mental health inpatients receive ECT in the UK annually (DOH, 2002; Rose, Fleischmann, Wykes, Leese & Bindman, 2003). Controversy exists about whether this treatment is beneficial and whether patients are satisfied with it. This is reflected in UK government guidelines which note that although some people find the adverse effects tolerable, others consider the side effects such as severe confusion and long term cognitive impairment unacceptable (NICE, 2003).

An early study by Freeman & Kendell (1980) examined the views of 166 patients through the use of a semi-structured interview schedule. On the whole, patients viewed ECT positively with 74% reporting improvements in their condition with only 13% reluctant to have it again. However, the researchers noted a possible positive response bias in that patients were interviewed by the psychiatrists involved in the administration of their ECT treatment. Having said that, they were surprised

to learn that 64% of the sample reported memory impairment and a striking 30% felt this to be permanent (Freeman & Kendell, 1980). In a clear response to this finding, the researchers published a follow-up paper which examined the cognitive function of 26 patients who had ECT against a control sample (Freeman & Kendell, 1980). Despite the researchers demonstrating that on several neuropsychological tests (verbal learning, face naming and logical memory), those who had been administered ECT performed significantly worse after accounting for factors like medication and severity of problem, they were reluctant to attribute this difference to ECT and emphasised the possibility of 'unknown variables' (Freeman & Kendell, 1980).

An interesting paper by Johnstone and Frith (2005) uses discourse analysis to deconstruct the language used in papers such as the one by Freeman & Kendell (1980) which effectively support the case for ECT. The authors draw attention to the ideological nature of report writing and the rhetorical language devices used by authors. They note that ECT recipients are often presented by researchers as passive, compliant, unassertive and trusting, especially when expressing neutral or positive views about ECT (Johnstone & Frith, 2005). When declining to be interviewed or criticizing ECT, they are constructed as unreliable, obstinate, irrational or politically-motivated. There is rarely an alternative identity whereby ECT recipients can be seen and treated as responsible and rational adults (Johnstone & Frith, 2005).

In light of this, an examination of the research base as a whole may help to alleviate the rhetorical nature of many of the findings. A recent systematic review of the literature by Rose et al. (2003) did just this and examined patient experiences and attitudes to ECT. Importantly, patients often report long-term memory loss after treatment. Across all studies (n=26), the evidence suggests that between 29% and 79% of patients experience autobiographical memory loss. It is often claimed through the use of neuropsychological testing that this is not a persistent deficit;

however, tests only formally measure one's ability to form new memories after treatment so there is no way as yet of empirically validating patients' claims of retrograde memory loss (Rose et al., 2003). The study also showed that reported levels of patient satisfaction with ECT were highly dependent on the methodology used. For example, patient led studies and research that was not conducted at the same hospital as the ECT was administered produced far lower rates of reported benefit as well as lower rates of willingness to have the treatment again (Rose et al., 2003).

Physical Restraint

In the UK, the dominant model of physical intervention in psychiatric services is control and restraint (Bonner, Lowe, Rawcliffe & Wellman, 2002). Developed by the prison service, the method was exported to mental healthcare in the mid 1980's. Research is unclear as to whether it decreases the overall level of violence on wards, but it seems that one of the reasons for its popularity is that staff feel more confident as a result (Bonner et al., 2002). However, some authors have concluded that due to its use of pain to control behaviour, it is in breach of human rights (Gournay, 2001).

Recent research used semi-structured interviews to investigate both staff and patient reactions to difficult incidents on a UK psychiatric ward in which the patient was physically restrained. Common antecedents seemed to be a disturbed ward atmosphere and failures in communication between staff and patients (Bonner et al., 2002). Most patients reported feeling terrified and embarrassed and staff also felt distressed and in an ethical dilemma over its use (Bonner et al., 2002). Patients stressed the need for better communication and understanding from staff, whilst staff themselves valued a debriefing period afterwards. An interesting point was that

temporary staff were viewed by both parties as having less invested in patient care and were perceived as more likely to use control and restraint. Furthermore, the experience of being restrained for some patients evoked memories of past abuse (Bonner et al., 2002). Although this study was a qualitative pilot project with a small sample size (n=12), it suggests that the use of control and restraint on a hospital ward can be potentially distressing for both patients and staff and highlights the need for more research in this area.

Discussion

The studies under review included a range of methodologies. For example, some were purely qualitative (e.g. Goodwin et al., 1999), some used mixed methods (e.g. Rogers & Pilgrim, 1993) and others were purely quantitative (e.g. Muller et al., 2000). When considering the benefits of methodological diversity in that findings are often more conclusive and robust as a result (Barker, Pistrang & Elliott, 2003), the field of inpatient views appears well researched, at least for adults in mainstream settings. However, it is important to appreciate methodological principles, namely to prevent conclusions being drawn that are not supported by the data. For example, interpretations of findings in the context of low response rates are often presented uncritically (e.g. Mckenzie, 2006; Morrison et al., 1999). Furthermore, there was very little discussion about the researchers' personal perspective or views relating to the hospital system or inpatient services, although notable exceptions include Goodwin et al. (1999) and to a lesser extent Freeman and Kendell (1980). There was also a significant lack of disclosure amongst the studies as a whole regarding funding sources and author affiliations. However, the Rogers and Pilgrim (1993) and Day et al. (2005) studies act as noteworthy exceptions.

Much of the research under review was qualitative with an emphasis on small scale studies with a few clear exceptions that used larger sample sizes such as Goodwin et al. (1999) and Rogers and Pilgrim (1993). Although the vast majority used forms of content analyses thereby strengthening levels of consistency across the field, several were unclear on their method of analysis (e.g. Rogers & Pilgrim, 1993; Bonner, 2002). There is also a need for more studies specifically focusing on carers' and other stakeholders' views and a need for more consistency in application of qualitative methodology. For example, some studies used standard interview schedules (e.g. Bindman et al., 2005) whereas others had versions created by the

researchers which were often not clear as to the form or content of the questions (e.g. Edwards, 2000). Another issue of note is the lack of extended samples of data or contextualised accounts, in other words it was difficult to ascertain whether this indicated a lack of research material or was due to publishing constraints.

Mixed methodology designs, although seen as more robust by compensating for the shortcomings of one approach, are not without problems too. For example, much of the quantitative research under review proposes a world view founded on positivist principles of accurate measurement of observable phenomenon (Barker et al., 2003). For example, large quantitative studies such as McKenna et al. (1999) and Kuosmanen et al. (2006) are all consistent with positivist principles. Although a valid rationale in its own right, positivism does not sit comfortably alongside qualitative assumptions of multiple world views and discovery-oriented research. Importantly for this review, mixed methodology studies in the field have often been presented uncritically (e.g. Day et al., 2005; Pescosolido et al., 1998; Mckenzie, 2006).

Quantitative methodology more often than not manifested itself in this review through the self-report questionnaire. Many of the studies examined used this form of data collection mainly to examine levels of patient satisfaction (e.g. Kuosmanen et al., 2006). However, despite being a cheap and simple method of obtaining feedback there are potential problems with validity. In other words, respondents can potentially deceive researchers by presenting themselves more positively. For example, a large UK study (n=254) based on a self report satisfaction scale conducted by Myers et al. (1990) found the overall inpatient experience to be positive. This does not fit neatly with the rest of the literature which presents the experience as generally negative. According to Goodwin et al. (1990) high satisfaction scores and a lack of response variability amongst self report scales may

actually reflect the difficulty people have in expressing genuine views to researchers. As noted by other authors, it is often in a person's interest to provide positive feedback to avoid upsetting staff, particularly in highly dependent settings like inpatient wards (Edwards & Staniszewska, 2000). Furthermore, global satisfaction scores give little indication of a user's experience of care and what they are pleased with or would like improved. Another problem is ambiguous wording in questions. For example, Myers et al. (1990) wrote that respondents originally misconstrued a question about single sex wards as referring to the gender of staff.

Participant response bias is explicitly discussed in some studies such as Freeman and Kendall (1980) and Rogers and Pilgrim (1993) but is more often omitted from study analyses. It was also not clear whether the majority of scales attempted to control for social desirability. Researchers have also expressed concern at the use of the term 'patient satisfaction' in that it garners a narrow response to the healthcare encounter rather than analysing the therapeutic or treatment process itself (Carr-Hill, 1992). It may also mean different things for both interviewer and interviewee and the notion remains unexamined and unproblematic in most of the studies under review.

Overall, the studies suggest that the inpatient experience for adults on mainstream mental health wards is consistently more negative than positive. Only a few studies such as Myers et al. (1990) and Muller et al. (2000) suggest otherwise. The findings also showed that the experience was stable over time, although it was only the Goodwin et al. (1999) study that incorporated a longitudinal component as part of its research design. Given the consistency of the findings as a whole and since many of the studies were drawn from countries other than the UK, for example Europe ,Scandinavia, Australasia and North America; the review also implies that the

inpatient experience is likely to be consistent cross culturally, at least with regard to Western societies.

A key feature of participant negativity was concern about a poor quality physical environment (e.g. Goodwin et al., 1999; Myers et al., 1990). Some studies emphasised being treated impersonally by care staff (e.g. Rogers & Pilgrim, 1993; Edwards, 2000; Wood & Pistrang, 2004) or a general lack of information provision (e.g. Kuosmanen et al., 2006) even with regard to simple rules such as the right to leave the hospital or not (Bindman et al., 2005). The review also suggested that care on the inpatient ward was coercive (e.g. Pescolido et al., 1998), even amongst those who admitted themselves informally (Poulsen, 1999). Coercive practice was also evident in inpatient treatments where the experiences of patients were very negative (Haglund et al., 2003; Bonner et al., 2002). Importantly, some studies suggested that coerced patients were less likely to seek care in the future or to comply with their treatment regimes out of the hospital (e.g. Hoge et al., 1998).

A main finding was that being an inpatient appears to be seen as more positive in the context of good relations between staff and patients. This was consistently encountered by the main studies (Goodwin et al., 1999; Kuosmanen, 2006; Rogers & Pilgrim, 1993) and again in the smaller sample studies (Edwards, 2000; McKenna et al., 1999; Poulsen, 1999) and includes both the qualitative and quantitative research base. It applies to all of the sections under review such as experience of treatment, levels of perceived coercion and general experiences of the ward. Significantly, it was also a main factor in a patient's willingness to adhere to medication regimes (Day et al., 2005).

Another consistent facet of the inpatient experience was lack of access to alternative treatments such as talking therapy which seemed to stem from an over reliance on medication, (Goodwin et al., 1999; McKenzie, 2006; Rogers & Pilgrim,

1993). A deficit in alternative approaches was also evident when dealing with difficult situations involving physical restraint of a patient (Haglund et al., 2003). In other words, the studies suggested the inpatient experience was set within a rigid and predominantly inflexible system of medical care. This was in contrast to a general wish for control expressed by patients as well as an overall desire for more talking therapy and improved access to information (Goodwin et al., 1999; Gray et al., 2005).

Despite the high level of consistency amongst the research under review, views did vary between respondents. For example, patients who had an admission forced upon them were more likely to view their experience as coercive and unpleasant (Bindman et al., 2005; Mckenna et al., 1999). Although perceptions of the inpatient experience were largely consistent between carers, staff and patients, (Hoge et al., 1998), differences such as carers feeling more burdened than patients perceived them to be (Cleary et al., 2006), and positive perceptions of procedural justice being held by staff and carers rather than patients (Hoge et al., 1998). Importantly, some studies suggested that clear and fair procedural justice was a significant factor for patients having a more positive experience (McKenna et al., 1999).

Notably, many studies did not differentiate between diagnostic groups and only a few studies such as Cleary et al. (2006) were able to demonstrate that those with disorders other than psychosis had more unmet needs than other inpatients. The particular function of a ward such as whether it was acute or rehabilitation was also almost entirely omitted from the studies under review. Ethnicity was subject to limited analysis but some studies did attempt to draw distinctions such as white versus non-white participants (e.g. Bindman et al., 2005). The Sainsbury Centre for mental health (2002) was notably the only source to focus on the experience of a

particular ethnic group and concluded that the inpatient experience was on the whole worse for black African and Caribbean inpatients. Gender distinctions also received little attention albeit one study suggested that women were less likely to experience relationships with staff as satisfactory (Kuosmanen et al., 2006). It is therefore still unclear how important demographic factors interact with the inpatient experience.

What is also unclear is the experience of those mental health inpatients incarcerated in specialist settings such as forensic or learning disability services. Although a good review exists examining the experience of forensic inpatients (Coffey, 2006), a lack of research material exists for adult mental health inpatients with a learning disability.

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Part 2: Empirical Paper

Mainstream in-patient mental health care for people with learning disabilities: service user and carer experiences

Abstract

Government guidelines promote the use of mainstream mental health inpatient services whenever possible for people with learning disabilities. However, the experience of this system for people without a learning disability is at best mixed. Also, little is known to date about how people with learning disabilities have experienced mainstream services up till now. This qualitative study explored the inpatient experience form both the service user, carer and community nurse perspectives for people with learning disability. Ten service users, nine carers and four community nurses were interviewed and interpretative phenomenological analysis was used to analyse the interviews on a case by case basis. The results supported previous findings in that the general experience of admission was mixed. For example, it was characterised on the one hand by providing respite but on the other as being disempowering and lacking in 'real' treatments. The study also showed that having a learning disability made the experience worse and emphasised the risks of neglect and difficulty around attaining help in the first place.

Introduction

While prevalence estimates vary, there is a consensus that people with learning disabilities are at increased risk of experiencing mental health problems. The figures tend to cluster around 40% for the learning disability population, compared to around 10% for the general population (Borthwick-Duffy, 1994; Deb, Thomas & Bright, 2001; Lund, 1985; Raghavan, 2004; Reiss, 1990; Rutter, Tizard, Yule, Graham & Whitmore, 1976; Taylor, Hatton, Dixon & Douglas, 2004). Frequently, admission of clients with both learning disabilities and a mental health problem to a generic ward occurs by default and clinical responsibility remains entirely with mainstream psychiatry (Chaplin & Flynn, 2000). It has been suggested that this model may have some key advantages, including patients being admitted locally, which may also allow for easier subsequent service provision and reduced stigma associated with utilising mainstream services (Chaplin & Flynn, 2000).

Potential disadvantages include a lack of trained staff, particularly around specialist assessment (Chaplin, 2004); problems of targeting interventions for someone with a dual diagnosis and the rapid pace of ward life (Day, 1993). General mental health services are also seen as poorly equipped and lacking in effective procedures to be responsive to the needs of this group (Fox & Wilson, 1999; Glasby, 2002). Furthermore, people with learning disability often come from protected environments and may unduly be affected by disruptive practices occurring on the ward, such as drug and alcohol use, violence and sexual activity (Chaplin & Flynn, 2000).

For the general populace, the mainstream psychiatric inpatient experience has been the subject of considerable analysis with notable studies like Goodwin, Holmes, Newnes and Waltho (1999) and Rogers and Pilgrim (1993). The authors used qualitative interviews and in the case of Rogers and Pilgrim (1993) questionnaire

data as well, to examine the experiences of large samples of inpatients (n=104 and n=516 respectively). They presented the inpatient experience as diverse, with patients appearing ambivalent about treatment and preferring the experience in context of good relations with staff (Rogers & Pilgrim, 1993). Negative experiences tended to outweigh the positive ones with patients expressing a need for being listened to, the importance of the tangible environment and a general lack of control whilst on the ward (Goodwin et al., 1999).

More recent research from studies utilising a semi-structured interview methodology widen the scope of these findings and indicate that psychiatric wards are associated with stigma and fear, treatments other than medication are hard to access and the experience characterised by a sense of disempowerment and at times danger (McKenzie, 2006; Koivisto, Janhonen & Vaisanen, 2003; Wood & Pistrang, 2004). Evidence derived mainly from questionnaire data suggests that coercion is a main feature of the admission experience with involuntary admissions associated with more negative experiences (Bindman, Reid, Szmukler, Tiller, Thornicroft & Leese, 2005; McKenna, Simpson & Laidlaw, 1999). Coercion often takes the form of leave restrictions and in extreme cases mechanical restraint (Kaltiala-Heino, Korkeila, Tuohimäki, Tuori & Lehtinen, 2000). Qualitative data suggests that patients have also reported feeling not respected and in the main, adopting a passive response to their admission (Olofsson & Jacobsson, 2001; Pescosolido, Gardner & Lubell, 1998).

In contrary to the general population, the evidence for people with learning disabilities is extremely scant. To date there has been only one study that has directly examined the experiences of people with learning disability in mainstream psychiatric inpatient wards. This is despite the involvement of service users being recognised as absolutely vital for service development (Department of Health, 2001).

Scior and Longo (2005) used a phenomenological qualitative methodology and interviewed 29 service users, 14 from mainstream services and 15 from specialist inpatient units, along with 20 carers which included an unspecified number of paid carers.

Mainstream settings were more likely to be described as disempowering and characterised by a lack of information and ambivalent attitudes toward medication, findings that are in line with the general populace (Rogers & Pilgrim, 1993). The study also suggested that negative experiences are likely to be exacerbated by having a learning disability and be more pronounced in mainstream settings. Disagreements between carers and professionals on the nature of service users' difficulties were also reported, with carers complaining that clients' mental health needs were overlooked and that difficulties were misattributed to their learning disability (Scior & Longo, 2005; Longo & Scior, 2004). Patients from mainstream settings were also more likely to feel negatively affected by other in-patients' disruptive behaviour. Interestingly, they also reported more experiences of peer support (Longo & Scior, 2004). This implies that mainstream settings may offer greater opportunity for integration and normalization. Although the Longo and Scior (2004) study is well designed and benefits from a high response rate, it is limited in that its participants all come from inner London and interviews were not tape recorded.

Other areas of relevant research include a qualitative study by Hawkins, Allen and Jenkins (2005) which emphasises the importance of information for people with learning disability. This study focused on learning disability service user experiences of physical interventions on generic mental health inpatient wards. Unsurprisingly, and in accordance with the literature for the general population, they concluded these to be primarily negative (Hawkins et al., 2005). However, they propose that such a view is exacerbated by a lack of understanding on behalf of the

service user with learning disability in regard to the process and context of the intervention. In other words, in the absence of comprehensive information, the experience of a physical intervention is likely to engender greater feelings of helplessness and promote the view that the ward is an unpredictable place (Hawkins et al., 2005). A lack of accessible information for people with learning disability on inpatient wards has also been highlighted by Strydom, Forster, Wilkie, Edwards and Hall (2001). This study used quantitative data to show that specific areas of inaccessibility relate to medication details such as information about side effects or contraindications, and proposed the use of dosage sheets and pictures to convey this more effectively.

Recent policies strongly advocate the use of mainstream services wherever possible and emphasise a need for mental health and learning disability services to work in close partnership (DOH, 1999; DOH, 2001). These issues are further developed in a number of documents aimed at guiding service providers in achieving these aims, namely 'Working Together' (Foundation for People with Learning Disabilities, 2003) which is aimed at fostering active partnership between services. 'Include Us Too' (Cole, 2002) also focuses on developing working partnerships by highlighting common ground between learning disability and mental health policy. 'Count Us In' (Foundation for People with Learning Disabilities, 2002) adds that services need to pay special attention to families and difficulties around life transitions for people with learning disabilities. The 'Green Light for Mental Health' (Foundation for People with Learning Disabilities, 2004) brings these initiatives together by providing a toolkit for services to achieve the above aims, namely through eliciting service user views on a range of mental health issues.

While there is thus a drive for increased 'main streaming', including when individuals with learning disability require inpatient mental health admissions, there

is extremely scant evidence on how they fare in these services and what the impact of all the recent guidance cited above may have been. The present study therefore aims to redress the lack of evidence in this area and further our understanding of the experiences of people with learning disability who use mainstream in-patient psychiatric services. The research questions posed are:

- What are the views and experiences of people with learning disability and their carers when using mainstream in-patient mental health services?

- To what extent is the experience of individuals with learning disability and their carers in line with government policies advocating effective working partnerships between learning disability and mental health services?

Method

Setting

The study was commissioned by the North Essex Mental Health Partnership Trust as part of a service evaluation plan. Participants were actually recruited from two healthcare trusts: one in Inner London, the other covering a large part of Essex with both urban and rural parts. At the time of this study, both NHS trusts mainly or wholly utilised generic as opposed to specialist mental health services for people with learning disabilities. Participants were drawn from 2 separate inpatient units in inner London and 3 units in Essex. The wards were similar in that they were all classified as 'acute' and were attached to general hospitals. However, some formed a component of a larger group of psychiatric wards with over 60 beds whilst others were the sole psychiatric service for that district with approximately 12 beds. The

specific wards where each participant stayed will not be described for the sake of maintaining confidentiality.

Ethics

The main ethical approval for the study was provided by the West Essex Local Research Ethics Committee (Appendix A1). Site specific approval was granted by Westminster PCT (Appendix A2).

Research Team

I joined the project at the point when main ethical approval was being sought. Apart from myself, there were two other members of the research team: my supervisor who acted as principal investigator, and a senior social worker and researcher who jointly conducted some of the interviews with me. Of the fifteen interviews completed as part of this study, all were conducted by me, 5 with the aid of the senior social worker. The data transcription and analysis was completed entirely by myself and discussed with my supervisor. The entire project was overseen by a research steering committee in Essex which had instigated the project to find out more about local mainstream mental health provision for people with learning disabilities.

Participants

Adult service users receiving care from learning disability services who met the inclusion criteria (previous admission to mainstream in-patient mental health care since June 2005 and verbal skills sufficient for participation in an in-depth interview) were identified as potential participants. Exclusion criteria also included unsuitability for the study such as being too unstable to give informed consent or

being too unwell to take part. All participants were interviewed either at home or in a day centre. Please see table 1 below for a summary of eligible service user responses to participation in the study.

Table 1. Eligible Service User Responses to Participation in the Study

Service users identified as eligible	Inner London (n=10)	Essex (n=16)
Agreed to take part in the study	5 (50%)	7 (44%)
Refused to take part after being asked	0 (0%)	2 (12%)
Specifically deemed unsuitable for participation by services	2 (20%)	7 (44%)
Not approached	3 (30%)	0 (0%)

Wherever possible their main carer pre and post discharge (defined as the person providing day-to-day care, including family and paid carers) was also included. Bearing in mind the potential vulnerability of service users and following detailed recommendations from the steering committee, it was decided rather than adopting a set procedure, to give service users the choice whether to be seen jointly with their carer, or on their own. In two cases the service users chose not be interviewed but consented to their sibling taking part in the study (cases 5 and 11). One service user from the inner London locality had to be omitted completely as it was later discovered they fell outside the inclusion criteria.

Ultimately, nine service users, nine carers and four paid carers were interviewed (see procedure below). All service users included were between the ages of 30 and 55. The essential demographic characteristics of service user participants are displayed in Table 2 along with relevant clinical information. Ethnicity has been summarised for the purposes of confidentiality. Related carer ethnicity in all cases matches that of service users and carer relationship status is summarised in Table 3. Paid carers were all community learning disability nurses.

Table 2. A Demographic and Clinical Summary of Service User Participants

Case	Gender	Ethnicity*	Diagnosis	Locality	Length of Admission in Weeks
1	F	WB	Mood Disorder	Essex	2
2	F	WB	Schizophrenia	Essex	4
3	F	WB	Schizophrenia	Essex	2
4	F	WB	Mood Disorder	Essex	2
5	M	WB	Not Specified	Essex	3
6	M	Non WB	Schizophrenia	Inner London	1
7	M	Non WB	Paranoid Schizophrenia	Inner London	10
8	M	WB	Schizophrenia	Essex	8
9	M	Non WB	Schizophrenia	Inner London	3
10	M	Non WB	Schizophrenia	Inner London	52
11	F	WB	Mood Disorder	Essex	4

*WB stands for White British.

Table 3. A Summary of Case Participants and Interviews

Case number	Interview number	Service Users	Carers	Paid Carers
1	1	Present	Partner	Community learning disability Nurse
2	2	Present		Community learning disability Nurse
3	3	Present	Sister	
4	4	Present		Community learning disability Nurse
4	5		Mother, Father	
5	6		Sister	
6	7	Present		
6	8		Partner	
7	9	Present	Partner	
8	10	Present		
9	11	Present		
9	12			Community learning disability Nurse
10	13	Present		
10	14		Father	
11	15		Sister	

Procedure

Potential participants were identified via learning disability healthcare professionals in both localities. They were initially informed about the research via several trust mailings and notices, as well as directly by the researchers via telephone, e-mail and attendance at meetings with key stakeholders. In line with requirements laid out in the ethical approval, the researchers did not have any direct contact with potential participants until they had consented to participate. All potential participants were given detailed information (Appendix B1 & B2) about the study and what their participation might entail by a familiar professional. This included mention of a token payment of £10 if they chose to take part. Service user details were only given to the researchers once they had agreed to take part or in some cases if they wished to discuss the research in greater detail to help them reach a decision whether to participate. Potential participants were then contacted by the researchers via telephone, any questions answered and an appointment arranged. With participants' consent, healthcare providers were also asked for some general information about each participant and their recent in-patient admission to allow the researcher to put the interview in context.

When the main researcher met with potential participants for the first time, the study was again outlined and informed consent confirmed. Participants were told about their right to withdraw from the study at any time, including their right to discontinue an interview. Where there was any doubt about a participant being comfortable with taking part or any signs of undue anxiety during the process, the researchers planned to terminate the interview.

As noted, service users were given the choice to be interviewed on their own or with another person present. Where this did happen, it was always a significant carer. During the joint interviews the researcher ensured that both service user and

carer were given a full opportunity to express their views. Where service users chose to be interviewed on their own, they were asked if they would consent to their carers being interviewed separately. If so, the researchers made contact with the carer via telephone and explained the study. If the carer agreed, information sheets (Appendix B2) were sent out and an appointment made. Informed, written consent was obtained from the carer and the interview conducted with full regard to the need for confidentiality.

Interviews

Interviews were digitally recorded with written consent from the participants and lasted between 30 and 90 minutes, taking place either at the participants' residence or in an alternative venue agreed between the participant and researcher. Interviews varied from having between one and three participants depending on factors unique to each person (table 3). Following this, it was decided to group the results on a case by case basis rather than contrasting what particular groups of participants said. Each case is therefore about one service user's specific admission experience, often containing multiple perspectives.

Interview Schedules

Semi-structured interview schedules were designed for this study with parallel versions for both service users and carers (Appendix C1 & C2). Topics were divided into 3 sections covering events leading up to an admission, the admission itself and post discharge reflections. In line with qualitative interview methods (Barker et al., 2003) the interview schedules were used primarily as guides and prompts for an in-depth conversation about the hospital experience. It was by no means intended that the researcher should ask all the questions or stick to a rigid

order. Rather, the researcher followed the participant's lead and only used prompts where the participant had not already covered the issue under investigation.

Anonymity

Anonymity was guaranteed to all participants. No recordings were labelled with identifying features and all transcripts were devoid of names of people and places that could be used to identify individuals. Digital recordings were destroyed at the end of the transcribing process.

Researcher's Perspective

Owning one's perspective is an important aspect of effectual qualitative research (Elliott, Fischer & Rennie, 1999). I had no material interest in the outcome of the study and did not have a concrete opinion about the relative merits of specialist or mainstream provision of mental health treatment for people with learning disability before carrying out the study. My area of interest is in working psychologically with people with learning disability along with the personal experience of being a mental health inpatient. My work as a psychologist in a community team for people with learning disabilities inspired me to work with this group, in particular the need as I see it to provide them with more of a voice.

Data Analysis

Tape recordings were transcribed verbatim with the aid of voice recognition software (Via Voice). The recordings were analysed thematically and in accordance with the principles and processes of Interpretative Phenomenological Analysis (IPA) (Willig, 2001; Smith, 2003; Braun & Clarke, 2006). See Appendix D1 for an example of steps in the data analysis.

Stage 1: Initial thoughts

I listened to the recordings several times over in an attempt to make sense of the discussion and to assign initial labels to surfacing ideas and meanings. These were recorded in the left hand margins of the transcripts.

Stage 2: Identification of themes

This involved a more systematic analysis in which I attempted to capture the essence of what was said in the discussion through thematic labels. These were recorded in the right hand margins of the transcripts.

Stage 3: Clustering of themes

This stage involved grouping related themes into clusters in order to provide them with an organizing structure. This was initially accomplished visually with quotes arranged on a large wall surface. Subsequent computer based analysis refined the groupings.

Stage 4: Thematic summary and quotations

A final list of super-ordinate categories and their constituting sub-themes (please see table 3 in the results section), as well as interview quotes which illustrate these was arrived at.

Credibility Checks

In accordance with methodological guidelines (Elliott et al., 1999), the credibility of the results was checked at regular stages with my research supervisor. This occurred 3 times during the course of the data analysis and involved in depth

discussion of the emerging themes. Analysis was helped through the use of paper representations of sub themes which could be manipulated quickly by researchers whilst maintaining an overall perspective on the findings (see Appendix D1). The thematic groupings were therefore continually refined and reworked whilst ensuring the emerging themes remained close to the wording and expression encountered in the raw data.

Results

Interviews with service users and carers elicited many strong opinions about the experience of being admitted to a mental health inpatient ward. The data was on the whole extremely complex and rich. Table 4 presents a summary of the main themes and sub themes resulting from the analysis. In the sections below, each master theme is introduced and its related sub themes described, starting with the more general experience of life on the ward and culminating with specific issues related to having a learning disability.

Quotes are in smaller font size with (X) indicating the service user or patient, (C) a family carer and (S) a community learning disabilities nurse. (I) signifies the interviewer. Throughout this section the terms 'service user' and 'patient' are used interchangeably to reduce repetition. Quotes are followed with a reference which should be read as follows, case number (in bold), interview number, page number and line numbers. For example, 1.1.2.3-4 would be case 1, interview 1, page 2 and lines 3-4. Ellipses (...) indicate material edited for brevity.

Respite

In all of the cases apart from case 5, at least some aspect of the admission was perceived as providing respite either for the patient or more frequently the carer.

Table 4. Overview of Themes and Sub-Themes

Main theme	Sub theme	Case Number and Locality (E=Essex; L=Inner London)										
		1E	2E	3E	4E	5E	6L	7L	8E	9L	10L	11E
Respite	Good Basic Care	*	*	*	*		*	*	*	*	*	*
	Respite for Carers	*	*	*			*				*	*
Disempowerment	Coercion		*		*			*	*	*		*
	Restrictions	*	*		*		*		*	*	*	*
	Submission					*			*	*	*	
A Daunting Environment	An Unsafe Place			*		*	*	*			*	*
	A Horrible Environment	*		*		*	*	*	*		*	*
Lack of 'Real' Treatment	Narrow Treatments	*	*	*	*	*	*		*			*
	Superficial Relationships	*	*					*	*	*	*	
Inclusive Versus Non-inclusive care*	Feeling Informed versus	*	*	*			*			*	*	
	Being None the Wiser	*		*	*	*	*		*	*	*	
	Having a Voice versus				*		*		*	*	*	
	Not Feeling heard	*		*		*			*			*
The Impact of Having a Learning Disability	A Barrier to Access	*	*	*	*	*	*			*		*
	Services At War	*	*							*	*	*
	Neglect	*		*	*	*	*			*		*
	Treated as 'Different'	*		*		*		*		*	*	*

* Unique main theme in that the sub themes are conceptualised as 2 different continuums for **information** and **being listened to**.

Good Basic Care

The majority saw the ward as providing good basic care. In particular this meant a place of containment. In view of the crisis which usually led to the admission, for many carers this was a primary function of the admission.

C: She's always been content to stay in there because in a certain way it's a safe world isn't it? You're fed, you're watered, someone reminds you that you should really go and have a bath...The responsibility of life in a sense is taken away from you and in her case I think that's what she wanted at that time.
11.15.11.2-8

In this context, patients talked about the good quality of the food, the chance to relax in a warm bed as well as staff "going the extra mile" to facilitate visits to one's family or liaise with other services.

C1: She was able to go out and get her cataracts done. The ward sorted that out for her so I was really pleased about that.
4.5.1.10-11

Specifically, patients found that staff just being within reach also served a supportive function.

I: So do you think it was helpful staying on the ward?
X: Yeah, because it's good to know that there is someone there because it gets that like there is no one there sometimes.
9.11.21.3-13

Individual staff members in particular were often singled out as being helpful and the medical team were frequently held in high regard. In some cases the other patients were also seen as a source of support.

C: They (patients) seem to be quite good, they are quite polite when they get to know you and because X had been there quite a few times its like "hi there, hows X"? They are making him feel quite good.
10.14.3.1-4

The accounts also referred to having 'things to do' on the ward as a source of enjoyment and respite.

I: So what did you do during the day?
X: Err, I did painting, art and craft.
I: How was that?
X: It was good yeah.
7.9.6.17-24

Respite for Carers

A key theme for many of the cases was that the admission provided carers with much needed respite. In some instances, accounts conveyed a sense of being supported or 'cared for' by ward staff.

C2: You can talk to the staff whenever you like. There is no problem there. You don't have to make appointments and that. You can easily have a chat to see how X is getting on. You can't fault the place really.
4.5.1.13-15

In some instances respite was a question of safety for the families affected by the patient's condition and for others it meant a well earned break from the exhausting caring role.

C: They kept him in here because he was violent towards me. He went to his mother's home and attacked his mother. You know it was for his own safety, also our safety that they kept him in hospital not to be violent towards me and to his mother.
6.8.3.33-36

Although some carers were unsure about the benefits of the admission, they were nonetheless grateful that the person was in hospital. Some informal carers were put in touch with other services during the admission, which they felt vastly improved their situation on discharge.

C: I think we eventually did get on to the learning disability social workers, and that's when things really started to take a turn for the better.
3.3.20.36-38

Disempowerment

In all cases apart from one, the inpatient experience was experienced as disempowering in some significant way.

Coercion

Participants talked about different ways in which service users were coerced by the system. Coercion is defined as the use of persuasion, inducements, threats or force to compel or restrain without regard to individual wishes (Collins, 1989). In this study patients and carers described numerous instances of enforced compliance.

Patients were often told that they either had to admit themselves voluntarily or face a section. In some cases they were not even told why they were being taken to hospital.

X: And em they picked me up in an ambulance and em they didn't say to me straight away that I was sectioned, they sort of like made out that like I sort of like had problems. I was thinking that it's something to do with my health.
9.11.23.30-32

In many cases treatment was perceived to be characterised by the principle that compliance was tantamount to recovery; for the majority that meant adherence to medication regimes. Patients also talked about other practices designed to obtain compliance such as the use of confinement and threats. This included staff threatening a female patient with restricted access to her daughter if she did not accept a specific discharge arrangement.

Restrictions

Dissatisfaction with numerous rigid rules and routines featured prominently in many interviews. Some patients disliked aspects of ward life such as having to always get up at a certain time or eat at a specified time or place. Importantly, restrictions were seen as a key factor in disliking the ward.

S: How could they have made your stay there happier?
X: Have your own room. They come and talk to you more. Have some free time. Let you have your dinner where you want. Let you have visitors in your own room.
1.1.19.32-39

Restrictions on physical movement seemed to be a common occurrence particularly not being allowed to leave the ward unaccompanied. Some patients felt they were unfairly restricted as a result of staff trying to appease other patients.

I: Were you allowed off the ward?
X: Well the other patients used to get upset when I was allowed out because a lot of them weren't, so I didn't get to go out as much as I could have.
6.7.1.32-34

For carers, access to patients' rooms was limited, often on grounds of safety and gender differences. This was experienced as frustrating particularly as in some cases the reasons given were unclear and just seemed to be part of general ward policy.

Relationships and communication between staff and patients were also described as subject to restrictions which was experienced as very unsatisfactory.

C: I found that they get allocated a person and that is their person that they are supposed to talk to. Well X didn't want to talk to anybody but there was a John in the office where she said, "I will talk to John." But John couldn't talk to her because he weren't her mentor; the other man was who she wouldn't talk to.
     11.15.13.1-6

Submission

There was a submissive quality to many of the accounts, characterised by patients wishing to maintain a low profile and please others.

X: I did what I was told, take the rough with the smooth. It would have been better to be at home - the only reason I went there was because I wasn't well, otherwise I would have been at home. I did what my dad wanted me to do.
     10.13.7.21-24

There was also reluctance by many to complain about anything for fear of bothering people. Some patients also felt the need to 'say the right thing' to staff to please them as well as to feel that they themselves had done something right.

I: Did you ever get access to a psychologist or counsellor while you were on the ward?
X: Yeah, when the people came in you used to go upstairs or wherever it was to see the person.
I: And did you talk to them about stuff?
X: Yeah, just like I'm sort of talking to you and that.
I: Right and how did you find that?
X: Well it was alright. We had a little room and we just had a discussion about things and there were certain things that they wanted you to talk about and then it was you know, just left.
I: Hmm.
X: The person was happy and I, well that's it isn't it.
I: Were you happy?
X: Was I happy? Ooh. Well, yes I feel that I done something good. Yeah, it's good to see someone come along and actually explain things plus I never had no sort of family coming along.
     8.10.12.18-43

Many patients also talked about the ward being better than nothing, for example 'better than prison', stating that they did not know anything else or realise there was any alternative.

A Dangerous and Unpleasant Place

An Unsafe Place

Approximately half of the accounts suggested that the ward environment was an unsafe place. This mainly centred on examples of violence perpetrated by other patients directed at either staff, the service user in question or to ward property. Unsurprisingly, the threat of violence was a source of great distress for both patients and carers.

X: This woman picks up a fire X extinguisher and throws it through the window and shattered all the glass. This guy, because I was going to the shop and did not get any alcohol for him, smashed up all the wall.
      10.13.6.43-45

C: I was so nervous, I was uncomfortable and I felt unsafe in the hospital...She (other patient) used to walk all around the ward frightening everyone, attacking the nurses and I was so nervous, my heart was pounding but because of X I wanted to stay because she might have attacked X.
      6.8.2.22-30

The ward environment was also experienced as unsafe due to, for example, illicit drug use and theft of personal belongings.

X: Half my stuff went missing anyway, my trousers my shirts and my bag. When I asked the staff where they were they did not know. I never got them back. When I went home people used to go into my room and steal my stuff.
      10.13.4.38-41

A Horrible Environment

As well as being unsafe, many accounts spoke of how awful the ward environment was. Some patients expressed very strong views about the inpatient service, for example claiming to"hate it over there". Carers' accounts generally focussed on the atmosphere of the ward, describing it as "depressing", "intimidating" or "frightening" with a sense of dread about visiting. Some felt the ward environment to be so awful as to be potentially detrimental to recovery.

C: It was horrible; it was horrible leaving him there. I don't think it's a pleasant place at all, I mean if I had bad nerves, that's the last place I would want to be. It's just so sparse and dingy; people with bad nerves don't want to be in somewhere like that. The bedrooms are horrible there, a lounge that smelt horrible, a dark old lounge. There's the smoking room that was all scruffy and their bedrooms have got nothing in you know, no nice colours. You need things like that. I've had a lot of um, nervous trouble and um, I couldn't be in a place like that.
      5.6.7.13-41

In addition, the environment was described by some as unhygienic and as a disruptive place with patients finding it difficult to sleep as others would be making noise long into the night. This included playing musical instruments, shouting or coming into other people's rooms.

Lack of 'Real' Treatment

All participants talked about general treatment on the ward as limited in some way.

Narrow Treatments

Participants noted what they saw as a narrow perspective on treatment in the inpatient environment; for example, patients often had nothing to do, either therapeutically or for leisure.

C: For the two weeks she was in there she spent the majority of the time in her room just talking to herself, wandering around the room and that was it. I can't say they did anymore than that for her because they didn't.
    3.3.10.8-10

In the midst of such inactivity, carers noted that any effort by staff to treat and interact with patients appeared to be focused on administering medication. There was a sense of irritation with this in some accounts.

C: I was surprised they don't have more for them to do up there you know. Things to relax them instead of just keep giving them pills all the time because that's what they seem to be doing, its just bunging them pills.
    5.6.46.6-19

Service users similarly complained about medication being the only or main form of treatment and in some instances came across as despondent.

X: When I was at that place it was 'more pills, the better the cure' sort of thing which got me down.
    8.10.6.32-33

Carers tried to rationalise this narrow perspective by suggesting it might be in the patients' best interests. However, there was also a sense of cynicism at the same time, implying it was about making the lives of staff easier.

C: If they are making too much noise and that, two pills and you'll find them asleep in the next three quarters of an hour. Because I suppose it's easier for them, perhaps best for the person.
    11.15.15.31-34

Superficial Relationships

Six of the cases under analysis made explicit reference to difficulty getting to know people, which appeared largely unrelated to the length of time spent in hospital. Ward routines, for example, not only seemed confusing but also involved high staff turnover with patients having to relay the same information '100s of times' and relationships with staff lacking any real depth. For several service users this sense of superficiality seemed a main factor in wanting to avoid future admissions to the inpatient service.

I: Would you want to go back if you got sick?
X: Probably not to the mental health ward.
I: Why not?
X: Cos I don't really sort of know them like I do elsewhere, cos I know sort of people in the other place better than I do down the mental health ward. I couldn't really get to know anybody down there.
    2.2.18.41-50

Participants conveyed a genuine sense that patient-staff interaction was just about 'doing one's job', and not about authentic interaction.

I: If anything was worrying you, could you talk to someone about that?
X: Yeah, one of them nurses I think, yeah.
I: So they were there for you?
X: Oh no, that's what their job was.
    8.10.9.8-15

During visits many families had to see their loved ones in a communal space, and described feeling 'on show' to the rest of the ward. This absence of privacy meant that communication often felt 'policed' and lacking in intimacy. In many instances, this was distressing for all parties with carers describing the ward as being 'cold'.

C: It is hard as sometimes X likes to be reassured with cuddles and things and it's hard in that open environment with people walking past you know. It's hard cos some people might get the wrong idea and you know it's a hard thing to judge. That's what I found.
    1.1.14.1-5

There was also a sense that patients found it difficult to build up lasting relationships with each other, even given a year long admission. They often did not consider other

inpatient "real friends", but just people to chat with at the time. The reasons given were mainly that other patients reminded them of being unwell, resulting in a reluctance to acknowledge familiar people following discharge back into the community.

X: I saw someone on the bus that I knew but I didn't say anything though, I just got off again.
     10.13.6.37-38

Inclusive versus Non-Inclusive Care

There was a sense that service users and carers either felt included and as playing an active role in their admission and treatment, or found themselves excluded from this process.

Feeling Informed versus Being None the Wiser

In approximately half of cases participants felt well informed by ward staff. In particular, ward reviews were generally perceived to have been useful exercises.

C: The meetings with the doctors and then the social workers I have to say were good. The doctors did actually explain as much as they could to me or as much as they understood.
     3.3.16.3-6

Both patients and carers in some cases also felt informed with regard to treatment. This involved understanding medication regimes and why a patient was placed on a section. Most of the information was given directly by medical staff and appeared to have beneficial long term effects with regard to quality of care in the community.

S: I think her boyfriends understanding is better now than it was beforehand because he used to kind of leave you to your own devices which meant that you didn't take your medication.
     2.2.12.43-48

On the other hand, in many cases there was a clear lack of information sharing. This related to treatment in that patients often did not know what their medication was for. There also appeared to be a lack of understanding on the part of both patients and carers about the nature of mental health problems.

I: Do you know what it's (medication) for?

X: Em, no. But they said that I was diagnosed schizophrenia but I don't know. I am not too sure what
it's for.
9.11.7.2-9

Both patients and carers also demonstrated uncertainty about the rules and regulations

on the ward, often being unclear about what they could and could not do. Carers

found it difficult to know who to liaise with and informal carers in particular often felt

kept 'out of the loop', having to find out what was happening from the patient.

C: I really had to find out what was happening through X. No one would tell me anything there and
again I found that hard to comprehend. It's like when I left I wasn't really none the wiser.
1.1.11.39-41

C: The hospital didn't tell us he was being moved to the mental health ward. I couldn't believe it
when I heard they had put him on there.
5.6.30.22-27

Having a Voice versus Not Feeling Heard

In approximately half of the cases service users and carers felt that their voice

was heard during admission. Some patients experienced being listened to by staff and

that their confidence to speak up increased as a result. These service users and carers

also felt consulted at meetings, especially with regard to treatment and felt that their

opinion counted.

C: After we changed the tablet they asked me which one I was happy with and I said I am happier
with the older one, so they changed the medication because I wanted them to do so. It was nice of
them to ask me.
6.8.6.32-35

In a similar number of cases did patients and carers feel they were not being heard.

Some felt when they tried to get help none was available. Other accounts suggested

that one had to 'fight' with staff in order to be heard, for example, when trying to

inform staff about medication side effects.

C: When I asked to talk to somebody there was never anyone there.
5.6.33.17-18

I: Did they talk to you about the side effects of the medication?
X: No, they didn't. They seemed to be not believing about the side effects till I fight with them you
know. Till I argued the case that I was experiencing these kind of things and then they realised that
it was true and they try to set me up with an appointment to solve the problem...in the end I won
the battle.
6.7.1.41-45

This sense of not being listened to was also felt in the context of families complaining to services about poor levels of treatment. The overriding feeling was that it was futile to do so and that services "had all the answers". Furthermore, it was clear that several carers experienced guilt about seeking help in the first place as they were implicitly told by professionals that they should cope on their own. Many also felt like they were not welcome as active participants in the care process.

I: Did you feel able to voice your concerns to any one?
C: No, no we didn't really which perhaps was wrong in hindsight. We should have made more of a fuss and said "what are you going to do with her and where is she going to go?" Or maybe the opportunity wasn't given to us at the time and we did not feel that we could speak up.
3.3.25.38-42

The Impact of Having a Learning Disability

There was an overwhelming sense that because of a person's learning disability, the whole admission experience was made more difficult.

A Barrier to Access

Attempting to access help was a disheartening and harrowing experience for many, with general health services like Accident and Emergency services (A&E) and general practitioners (GP's) acting as gate keepers. The experience was characterised by a lack of professional knowledge in the areas of mental health and learning disability by healthcare staff at the point of trying to access help.

I: What's your experience of going to A & E?
C. Its very very harrowing. I mean you're sitting there right, you could be waiting for hours and the doctors they haven't got that much of a clue on the mental health side of it.
I: Right.
C. Its like all these questions are asked and you know, they really haven't got much of an inkling. Sometimes you feel like banging your head against a brick wall. Then they'll get someone else in and it's repeated until it dawns on them that we have to get somebody from the mental health ward to come over.
1.1.3.30-47

There was also a sense that mental health staff attached to the ward were reluctant to even assess someone with a learning disability. This was described by some as

"fighting, a constant battle", so intense that on occasion carers had to resort to phoning

the police or threatening to abandon the person in order to secure an admission.

C: So I left her down there, which might sound a bit cruel but I don't think it was..."We can't get on
    with our work", I said, "and I can't get on with my life". You know, you shouldn't have to resort
    to things like that. They didn't like it at all.
    11.15.2.24-32

Frustration and anger with services was also provoked by marked delays in receiving

help, with carers having to 'hold' the crisis while professionals made up their minds.

Carers felt devalued and talked about their sense of frustration and powerlessness in

the face of the help seeking process, often feeling misunderstood and looked down

upon by the people they were seeking help from.

C: In fact the doctor said, "Relatives love looking after people". I said, "Yeah, they might if there's
    about half a dozen of them but when there's just one you just can't do it".
    11.15.8.25-27

Having to manage the crisis adversely affected all parties, in other words a person's

network of formal and informal support. This included paid carers who had to work

unacceptably hard in order to resolve the situation.

S: It was me on my own and I had to drive her on my own all the way. I don't think I'd ever do it
    again, at 12 o'clock at night if I remember.
    1.1.7.8-11

Services at War

Disputes between mental health and learning disability services pervaded the

accounts, a situation characterised by a lack of joint working. This was a salient

feature for many of the cases. It was also a perspective shared by both community

nurses and relatives of the patient.

S: This thing about joint working and dual diagnosis needs a lot more work because he is either yours
    or he is ours and I know that we are quite clear that we work with learning disabilities and a
    percentage of those clients also have a mental health problem but to get some of the mental health
    team to work with us so that we can give them the best possible care package for their needs
    doesn't always happen. So it is either down the route of learning disabilities or down the route of
    mental health.
    9.12.16.28-35

Mental health services were often perceived as reluctant to act and as overestimating

the extent of the resources available to learning disability services. They would often

make the decision not to admit someone without consultation, the most frequent reason being that any problems are caused by a person's learning disability. At times carers felt this was really about services using an excuse to avoid having to act.

S: It's that initial point where it's no, they've got a learning disability so we don't want to go there. You've got your own service, your own beds, but that's just not the case.
2.2.19.40-43

Such disputes often led to heated disagreements between members of the different services over the patient's right to be admitted. This was clearly distressing for healthcare providers as they felt they had to use threats and gave the sense that the services were 'at war' with each other. The upshot was that both patient and carer were adversely affected.

S: The constraints and loopholes that we have to jump through to get people in is very, very frustrating. It could have become quite an unprofessional conversation because people were very, very angry and also I felt that X could have been put at risk and was put at risk. We don't want to use any kind of threatening behaviour, we don't want to be using that in our practice at all. But it becomes a them and us, and I don't think it should be like that.
2.2.19.30-37

Neglect

A salient issue for many participants was that staff did not accommodate or properly understand a person's learning disability whilst on the ward. Unfortunately, in many cases this led to neglect, especially in the context of communication difficulties.

S: What I found lacking was staff understanding of people's special needs...They would assume that X understands everything, but in fact X's level of understanding is very, very limited. Although she appears to understand everything, if things are too complex there's no way X will make sense of it.
4.4.22.30-45

Participants described some instances when service users could not communicate their needs to staff and did not receive appropriate treatment after suffering serious accidents on the ward.

C: She'd fallen and they waited all day for an ambulance to take her over to the accident and emergency.
3.3.12.42-44

C: He was made to you know, walk about with that broken hip.
   5.6.39.4

Some carers felt that patients were discharged without adequate assessment and that individual needs were not properly accounted for. A particular criticism expressed by many carers was that staff did not know or care about what was going on and preferred to "leave patients to their own devices". Carers felt such staff attitudes arose from a failure to recognise support needs and an assumption that patients with learning disabilities could do things for themselves in the same way as other patients on the ward.

C: So when he was put on there, all the others could do things for themselves, he couldn't and he was just left to it you know. He just didn't know how to do anything. I went in one day and there was sick all over the floor of his room, he was sitting on the chair with just a pair of pants on and I couldn't find any clothes for him and he was freezing.
   5.6.8.17-34

Treated as 'Different'

The accounts portrayed an overwhelming sense that people with learning disabilities were seen as different by services and other patients alike. Staff might refer to them as 'oddbods' or insinuate that it doesn't really matter where they go. Other patients were seen to be quite judgemental at times.

C: It's almost as if, well they're, they're silly so they won't care where they stay isn't it?
   5.6.41.43-44

I: Did you get to know the other person in your room?
X: I didn't like em. They judged me. I'm different to them.
   1.1.18.3-9

X: I had a few friends but most people tormented me and called me names, they used to call me names you know. That wasn't very nice.
   10.13.2.34-35

Staff carers perceived other patients to be overly distant from the person with learning disabilities and not as friendly as they might be.

S: Other clients there haven't got learning disabilities and they know this client has. The other person who is sharing the room seems to distance themselves away from them because that person has a label and I suppose they are scared and not understanding about what the person is like but they don't seem to be as friendly to that person in the room.
   1.1.14.9-16

Discussion

The results on the whole were rich and the interviews genuinely moving with participants appearing to give a very honest and personal view of the admission experience. Accounts presented a complex and mixed picture with the most consistent view being that having a learning disability made the experience all the more difficult. Given this, I will begin the discussion with the most important result, namely the impact of having a learning disability, and move on to considering the wider findings.

At the outset it is important to note that there was no noticeable variation across localities for any sub-theme, except that none of the participants from the inner city locality felt that they had not been heard by ward staff. Due to the small sample size it is difficult to conclude anything definitive from this, albeit it does suggest that some services are more successful in involving and consulting service users. Further research would be useful to examine in detail what aspects of staff behaviour, ward atmosphere, procedures, or resources contribute to service users and carers feeling heard.

Participants in the current study perceived a crucial consequence of having a learning disability as a barrier to accessing help in the first place. This is in line with previous findings where help was deemed to be delayed in its response or staff attitudes seen as rejecting (Longo & Scior, 2004). However, people with mental health problems are often discriminated against at the point of access (Rogers & Pilgrim, 2003). Detailed accounts of the numerous difficulties in trying to get help in the current study suggest that significant mental health problems in the presence of learning disabilities often place the person and those around them at greater risk of not receiving help. Several participants in this study felt that the reluctance of mainstream mental health services to engage with individuals with learning disability and their

carers arose from an a priori assumption that all their problems are associated with their learning disability. One might argue that such attitudes are both a reflection of historical discrimination and the medicalisation of learning disability (Fredman, 2006), ultimately serving as instruments of exclusion. The results from this study therefore suggest that much needs to change before 'mainstreaming' is likely to meet the needs of the learning disability population.

The sub-theme 'services at war' reflects a lack of joint working which is in stark contrast with the emphasis on joint working between learning disability and mainstream mental health services in government policy initiatives, particularly the 'Valuing People' White Paper (DOH, 2001; Foundation for People with Learning Disabilities, 2004). However, the accounts themselves do not present the perspective of mental health services and it would be unfounded to make assumptions about attributing blame. On the basis of this study alone then, one can go only as far as saying two things with any confidence about service disputes. One, that there is evidence to show that a lack of joint working occurs, independent of locality, when a person with learning disability is admitted to mainstream mental health services; and that disputes between services have adverse effects on both the individuals and systems involved. A useful question for further research would be to obtain the perspective of mainstream mental health service providers who are missing from empirical evidence. They might, for example, stress a lack of resources within mental health services, which did not significantly feature in the current results.

Neglect was also a dimension of the accounts, with participants painting a fairly depressing picture of poor treatment as a consequence of having a learning disability. This supports previous findings (Longo & Scior, 2004; Scior & Longo, 2005), but seemed to occur with greater frequency in this study. A 'lack of

knowledge' on behalf of staff as a source of neglect was often cited as a main factor across both studies. However, the current findings introduced a new concept underpinning neglect, namely an 'assumption of competence'. This could well be about a lack of understanding of learning disabilities by ward staff, but may also reflect a tension between the philosophies and practices in mainstream services. In other words, an emphasis on self determination or independence is seen as essential to treatment plans within mainstream psychiatry (Gelder, Mayou & Cowen, 2001). This may predispose services to underestimating the often significant support needs of individuals with learning disabilities.

The final sub-theme specifically related to having a learning disability concerns the idea of being treated as 'different' which was a salient issue in 6 out of the 11 cases under review. This again provides a fresh perspective on what was perhaps seen as isolation, disbelief or unfriendly fellow patients in previous findings (Scior & Longo, 2005; Longo & Scior, 2004). The concern here is that service users were clearly at risk of being bullied, stigmatised and generally discriminated against by others on the ward, simply because they had a learning disability. This is particularly worrying considering that there is much evidence to suggest the inpatient environment is quite unsafe regardless of a person's cognitive capacity (Goodwin et al., 1999; Wood & Pistrang, 2004). This has important implications for the mainstream versus specialist learning disability services debate and suggests that the current focus on mainstreaming for people with learning disabilities may at times promote overall levels of discrimination rather than reducing it.

Moving to the general findings, a theme common to all cases apart from case 5 was that the admission provided some form of respite for all parties. Good *basic* care was found across all localities and cases, specifically the ward being seen as a secure

and containing place. This is very much in line with previous findings. Goodwin et al. (1999) for example, found that inpatients valued practical support, ward activities and the friendliness of staff.

It is important to discuss a particular issue concerning case 5 in that this person had no diagnosed mental health problem before the admission and was only admitted to the mental health ward due to a lack of beds in the main hospital. Although the person fitted the inclusion criteria for the study and had many useful things to say about life on a psychiatric ward, one might see the case as a potential outlier. In other words, respite was actually a feature for all cases where the person was admitted for a mental health reason.

The admission serving as carer respite was also pertinent. Carer views of the inpatient experience are limited within the mainstream literature so it is difficult to say with confidence whether respite for carers is something typical for general admissions or not. However, available evidence suggests that for patients with a learning disability, carers do experience the admission as providing respite (Longo & Scior, 2004) albeit less than the current study suggests. Importantly, a new finding to emerge was that in some cases the admission served to relieve the long-term carer burden, in particular by educating families and putting them in contact with previously unknown sources of support. This was essentially about forging ties with the local community, housing and learning disability services. This links to the notion that mainstreaming can be beneficial by putting people in touch with more locally accessible resources (Chaplin & Flynn, 2000).

Disempowerment also emerged as an important facet of the admission experience in all cases apart from one. In a sense this theme encapsulates the idea of a 'lack of control' in the inpatient setting, a well documented finding in previous studies

(Goodwin et al., 1999; Rogers & Pilgrim, 1993; Scior & Longo, 2004). There was ample evidence of coercive practices as well as restrictions placed on patients and carers. For example, most of the patients in this study were presented with the 'choice' of voluntary admission or being sectioned, which links into the widespread use of quasi-coercive practices as outlined by Monahan, Hoge, Lidz, Roth, Bennett, Gardner and Mulvey (1995).

A new perspective to emerge from the findings that is not well documented in previous research is the concept of 'submission'. Service user accounts in this study were characterised by a wish to keep a low profile and "not to make waves". Although it is difficult to ascertain whether this is a feature of the general admission experience or not, several factors indicate that it is more associated with having a learning disability. Firstly, submissiveness is not easily supported by previous research, suggesting it is something unique to this population. Secondly, submission relates to the much cited occurrence of 'acquiescence' on the part of people with learning disability (Clare & Gudjonsson, 1993; Sigelman, Budd, Spaniel & Schoenrock, 1981). Acquiescence or the tendency to submit to more powerful others was evident in accounts by a wish to say the right thing and "not to bother anyone". Worryingly, an acquiescent stance acted as a significant risk factor whilst on the ward as it seemed to hinder a person from receiving appropriate treatment, a particular concern for case 5. One might therefore say that people with learning disability who experience mental health problems of a severity to lead to an inpatient admission are at an increased disadvantage when attempting to make their views heard. Ways to enable them to feel their voices are heard should be an area for further research, as noted earlier and in line with policy proposals (Foundation for People with Learning Disabilities, 2004).

There were few surprises with regard to the findings concerning the ward as an unpleasant environment. The majority of participants found this to be the case with a particular emphasis on disruption and a lack of safety which fits very well with previous evidence both in the general and learning disabilities literature (Goodwin et al., 1999; Rogers & Pilgrim, 1993; Scior & Longo, 2005; Wood & Pistrang, 2004). Similarly, a narrow range of treatments has been a finding of previous studies, particularly an over emphasis on medication (Gray, Rofail, Allen & Newey, 2005) and difficulty in accessing treatments other than medication (Baker, Lovell, Easton & Harris, 2006).

The idea that relationships were superficial in quality fits less neatly with the existing general literature. Goodwin et al. (1999) note that inpatients appreciated close relationships with staff, which have been shown to be important in the process of recovery (Chafetz, 1996; Rogers & Pilgrim, 1993). In view of communication difficulties and social skills deficits, for example, which are closely associated with learning disability, it would seem reasonable to suggest that inpatients with learning disability may experience even greater difficulties in forming meaningful relationships in this environment.

Previous literature cites lack of information as a key feature of inpatient settings (Goodwin et al., 1999; Kuosmanen, Hatonen, Jyrkinen, Katajisto & Valimaki, 2006; Scior & Longo, 2005) and this study was no different. However, in several cases participants felt informed especially at the ward review and carers subsequently feeling better equipped in their caring role due to feeling informed. This is a different perspective to that of earlier research on people with learning disability (Scior & Longo, 2004) and suggests that attitudes toward the sharing of information may slowly be changing in line with government policy (DOH, 2001). Also contrary to

previous findings in the general (Koivisto et al., 2003; Pejlert, Asplund & Norberg, 1995) and learning disability literature (Scior & Longo, 2005), some participants felt able to speak out and listened to, although it should be stressed that this was far from commonplace.

Methodological Issues

Like other qualitative research, the findings are based on a small sample that in effect was selected by service providers who may have had a vested interest in a certain outcome. However, the very mixed findings and high percentage of identified 'cases' which participated in this study suggest that sampling bias was limited.

In terms of the validity and quality of the accounts, one could start by reflecting on the interview schedule itself. This had a distinct structure in that it took a chronological approach, namely focusing on admission, hospital experience and discharge. Previous authors such as Myers, Leahy, Shoeb and Ryder (1990) have noted that service user research often fails to tackle what is in effect a very complex ecology. In other words, it does not fully appreciate a person's often impoverished life prior to an admission as well as the complexity of the hospital experience. Although the interviews asked about events leading up to the admission, they did not take a longitudinal perspective which might have, for example, highlighted that a person's point of comparison is often a poor one (Myers et al., 1990), not least in leading to a sense of submission.

The decision in conjunction with the research steering committee to give service users the choice to be interviewed either on their own or with their main carer presented a unique methodological challenge. Service users made different choices, several wanting their key nurse present either in addition or instead of a relative.

Although this differed from an original proposed methodology of discrete groupings, it was felt important to respect service users' choice. In view of requirements laid down by the ethics committee that all early communications with service users were done indirectly through service providers, one might argue that the choice expressed was in fact likely to be aligned with the wishes of those service providers. While this might be true, there was little evidence of disagreements between service users, carers and community nurses during the interview process.

Participants themselves appeared honest and genuine and were often grateful to have the chance to talk about their experience. In some cases, carers produced written testimonies that were part of ongoing complaint procedures against service providers. As well as providing richer accounts for the purposes of data collection, the written material may also have served to lessen accuracy problems associated with retrospective verbal recall (Eysenck & Keane, 1994). Another potential pitfall was the process of the research itself, such as the difference in meaning between what a participant said and the researcher's own interpretation. This is common for much of qualitative research (Barker et al., 2002), and my interest in the hospital as institution and providing a voice for learning disabilities service users will have taken both the questioning and analysis in a certain direction.

In terms of the analysis, the themes reported are not meant as objective categories, but as the researcher's interpretations of what was a very large and rich dataset, some interviews exceeding 10,000 words in length. The categories in a way are shaped by the historical literature and the researcher's interpretation of that, whilst also closely reflecting the unique insights and experiences of the people who took part in the study. To address this limitation, additional credibility checks might have been conducted such as obtaining more researcher perspectives during the analysis or

actually checking the themes with participants themselves. (Braun & Clarke, 2006; Barker et al., 2002).

Conclusions

The results suggest the admission of a person with learning disability to a mainstream mental health service engenders complex and mixed responses. In most cases it was experienced at least to some extent as respite and occurred in the context of a crisis for which help had been sought over an extended period of time. Alongside this stand some very negative accounts of neglect, disempowerment and discrimination. There are some signs that recent policies and guidance may be having an impact on some services and individuals, but the results suggest that there is a long way to go until key values such as choice, inclusion and working in partnership are a common reality when people with learning disability are admitted to mainstream mental health services.

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Part 3: Critical Appraisal

Introduction

Examining the experience of being admitted to a mainstream mental health inpatient ward from the perspective of a person with learning disabilities has on the whole been extremely rewarding. That is not to say that the process has been without its challenges, dilemmas and occasional arduous times. The following review examines this process from the perspective of the researcher and attempts to present a holistic vision stretching from conception to completion. Personal reflections are discussed regarding the initial idea as well as an analysis of the unique challenges presented by the study. This includes ethical and consent challenges, staff issues and the challenge of incorporating multiple perspectives. The wider implications of the study are also reflected upon.

Personal Views

I have been strongly aligned to the idea that it is important to listen to those on the receiving end of help, if only to reassure the *help provider* that what's been done to the *help seeker* is effective. In this case it is the provision of inpatient mental health care to an already vulnerable group of distressed people and their families.

The experience of being a mental health inpatient is a topic not unfamiliar to analysis in wider society. The obvious example is Ken Kesey's (1962) popular work of fiction, One Flew over the Cuckoo's Nest. Essentially, it is the institution that is under scrutiny here, not necessarily its form. The hospital as institution has been of significant interest to me and an important aspect of my clinical experience, inspiring my interest in this study from the start. Essentially, by eliciting inpatient views I see the institution encouraged to reform through reflection. One way this might happen is through exposure, for example by bringing power inequalities to the fore or making

visible practices that serve to coerce. Equally, exposure may also highlight positive qualities which help seekers value and that are essential to effective treatment. This can only be of benefit to all parties, a view appreciated by governmental policy which seeks to emphasise the importance of service user views, particularly for people with learning disability (Department of Health, 2001).

Importantly, clinical experience has led me to reflect on the often tenuous nature of this fundamental principle, namely effectiveness of health provision and the incorporation of user views. For example, a service user undergoing assessment in a learning disabilities service responded to my question about how they were coping with their learning disability with, "what's a learning disability?" This illustrated to me the extent to which professionals can make wrong assumptions, for example that people with learning disabilities are a homogeneous group and that they define themselves in the same way we define them. It also stresses the importance of giving them more of a voice so that assumptions like these can be challenged. Following this, I have used the term 'learning disability' throughout the study more as a convention rather than as an objective term. I have also declined to use a shorthand version like 'LD' as this could be seen as disrespectful.

Challenges

The study presented a range of recruitment and methodological challenges which centred on ethics and consent, staff difficulties, the relative merits of multiple perspectives and feeding back. A table summarising the relevant issues encountered in this study is shown below and should be of particular use for those conducting future research with this population.

Table 1. A summary of the relevant challenges encountered in the study

	Challenges
Ethics and Consent	• Ethics committee requires a site specific assessment to be conducted when expanding the zone of recruitment despite being a purely qualitative study. • The committee specifies that identified participants should be able to name anyone to accompany them during an interview. • Researchers are not allowed to make contact with potential participants until initial consent has been taken by other professionals close to the person in question.
Staff	• Some clinical staff reluctant to involve identified participants with the research. • Many front line clinical staff especially overburdened and overworked.
Multiple Interview Participants	• Advantages: A truer reflection of closer networks of support / Richer data elicited through discussion. • Disadvantages: Potential for censorship / Researchers unable to control who takes part in the interview.
Analysis	• Case by case design versus comparison groups design.
Feedback	• A need for tactful feedback of sensitive and often negative findings.

1. Ethical and Consent Challenges

A major stumbling block in recruitment was experienced as a consequence of decisions by the main ethics committee. In summary, before the researchers could get involved, participants had to be identified firstly by an initial group of professionals who then passed on details to another group identified as working closely with the participant in question. They then explained the study and took formal consent. It was only after this that researchers could contact participants and arrange a suitable time to meet, explain the study again and take a second formal consent.

However, the initial group were clearly over burdened and lacked the relevant knowledge to identify participants. In practice, this meant that the official consent process was unwieldy. Identification had to be done direct with each community team whilst at the same time keeping in line with the principles set out by the committee. Namely, that participants had to be recruited by their paid carers. However, front line teams had little to no knowledge of the project and lacked enthusiasm for it as they saw it as service evaluation. Frustratingly, this slowed the process considerably and meant that participants had often moved away, forgotten or become unwell again by the time the researchers were able to make contact. Crucially, initial consent rested with individuals who had minimal interest in the study. The overall result was confusion for participants in that there was often a large time gap between hearing about the study and taking part in it. In some cases, participants found it difficult to remember they had agreed to participate.

The purposes of an ethical review are to protect both participants and the institution from harm and to comply with the regulations of the grant givers (Barker, Pistrang & Elliott, 2003). The justifications cited for the consent procedure were to reduce the amount of information given to the researchers as well as the potential

anxiety of participants (Appendix A1). However, the effect was the opposite. Anxiety was raised and the researchers often received superfluous information about people who were unable or ineligible to take part. The latter was due either to the time it took to complete the process or a misinterpreting of inclusion criteria in the first place by community staff.

A further constraint occurred around the decision by the committee to impose the need for a site specific assessment (SSA) should the research need to be extended. Considering the recruitment difficulties in Essex it was necessary to extend the study to Inner London. However, according to the National Research Ethics Service (NRES) regulations, it is not appropriate for qualitative research to undergo SSA. No formal reason was given for the requirement of SSA apart from a verbal reference to vulnerable adults. I would speculate this implies a concern around capacity to give consent and would seem to tie in with the current government emphasis on the implementation of the new mental capacity act (DOH, 2007). It also seems to echo new guidelines from the NRES that state SSA is required for any new application involving adults who are unable to consent for themselves (NRES, 2007). If this were a reason, then hypothetically the decision was influenced by an assumption of incapacity for people with learning disabilities. For those meeting the inclusion criteria for this study, mental capacity simply was not a concern.

2. Staff Challenges

A further hurdle lay with the attitudes of staff on the ground in that access to participants was restricted. The reasons given fitted into two broad categories which were either "you won't get good data" or "you will do them harm". This prevented access to approximately 50% of those named as eligible to be included in the study. I have summarised the reasons given for non-participation by staff below:

Table 2. A Summary of Reasons Given by Staff for Participants not taking part in the Study.

Main category	Sub-category
You won't get good data	The person is too agreeable
	The person is too shy
	The person doesn't like doing research
You will do them harm	The person is unstable
	The person is not well enough to take part
	It will be too upsetting for the person

The most commonly cited reasons were either the person was unstable or that they were too agreeable. On the one hand it is reasonable that a person might be too unwell to take part. An assessment of instability is therefore an important consideration and one would not expect to interview anyone who was unwell. Considering that people with learning disability are under-represented in the first place (DOH, 2001), I feel that it is unacceptable to deny someone a voice simply because they are perceived as too shy or tend to acquiesce. Considering this study highlights acquiescence as a potential risk factor for a person with a learning disability on a mainstream psychiatric ward, one might go a step further and postulate that it also acts as a barrier to getting heard in the first place.

Possible reasons for this response might be that staff are simply reflecting wider social stereotypes around agreeableness and shyness in people with learning disability. Staff could also have been seeking to censor the study for fear of negative

findings. This would fit the ambivalent attitude encountered by the researchers. Lastly, and for me this fits more closely with the research experience, individuals close to the person may have found themselves protecting them from potential adversity such as social activity (Goldberg, Magrill, Hale, Damaskinidou, Paul & Tham, 1995). Again, this may account for staff ambivalence and is linked to stigma in that it is motivated by the perceived consequences of having a learning disability. The implications for the sample were that those interviewed may have been vetted by staff.

Despite staff being a hurdle to recruitment, notable was the enormous drain that the access barrier into appropriate treatment inflicted on them. I was particularly struck by the difficulties encountered by community nurse participants who on the whole seemed very overworked and had clearly suffered an arduous time trying to secure help for the person in their care. There were examples of staff cooking and cleaning for service users whilst an admission was being negotiated and even staying overnight in their homes simply because no one else was available. This has very important implications for service delivery and raises concerns about staff retention and burnout as already highlighted by some professional organisations (Community Practitioners' and Health Visitors' Association, 2007).

3. Account Validity: Multiple Interview Participants

The design of the study meant that some interviews were conducted with several people present. Despite being aware of the potential censorship that can occur when talking with more than 1 person at the same time, on the whole the research team felt that discussion really benefited. For example, it allowed a synthesis of multiple perspectives to be captured and initiated the idea of analysing the data on a case by case rather than an individual basis. Interviewing several stakeholders at once is in a sense analogous to some of the strengths of focus group methodology such as

developing culturally specific hypotheses, conversations taking on a life and direction of their own and accounts possessing greater ecological validity (Alvidrez, Azocar & Mirander, 1996; Kitzinger, 2005).

However, a number of potential threats to the validity of these accounts did arise as a result. For example, there were times when community nurses felt obliged to defend inpatient services from too much criticism from service users and their carers. This manifested itself in overt contradictions as well as talking over people. This led me to question on the one hand the validity of service user accounts but also to consider this diversity of opinion in terms of the different roles individuals had during an admission. For example, nurse participants have a dual loyalty to both the patient in their care and the institution who pays them. Also, carers often felt over burdened and tended to emphasise the respite benefits of admission. Fortunately, this was an irregular occurrence and generally I felt each case was presented collaboratively. My impression was supported by the cases in which people were interviewed separately and almost always offered a consistent picture. However, I felt it important to be mindful of these processes and often drew attention to the disagreement or returned to censored issues later on in the interview. I felt this at least attempted to make sense of conflicting views.

4. Reflections on the Analysis

The decision to use Interpretative Phenomenological Analysis (IPA) as well as interpreting the data on a case by case basis took the research in a particular direction. For example, it will have emphasised the collective experience over the individual one. While this could be viewed as a potential weakness, I feel it may reflect the reality of the lives of people with learning disability more accurately. In other words, they tend to have greater support needs and are more reliant on professional networks

of care than the non learning disabled population. Given this, multiple perspectives are of particular relevance here and should perhaps be a design consideration for future research. I was also struck by the shear breadth and depth of some of the interviews and was often surprised at such 'richness' when I read back over transcripts. I think this emphasises the importance of recording interviews and transcribing verbatim. It also puts into focus how involved one is at the time of conducting an interview and how difficult it can be to recall with accuracy what was said.

The original plan for this study was to interview a 'control' group of service users without learning disability, and matched to the current sample. I feel the research would have benefited from this addition as it might have made the impact of having a learning disability on the inpatient experience seem more obvious and conclusive. Another plan was to conduct a number of focus groups with mental health inpatient staff. Again, this would have provided another key missing voice and perhaps made conclusions more definitive, especially when trying to understand the reasons behind the positive and negative aspects of an admission. As the project is ongoing, it is hoped these groups are recruited in the near future and the data incorporated with the main findings from this study.

5. Feeding Back

Part of the original aims of the study was to feedback the results to all of the stakeholders. In terms of the commissioning body, the results were presented to a managerial committee which included senior clinical staff. Those present also included representatives from the Department of Health and leading figures from the Foundation for People with Learning Disabilities. Although this enabled the findings to potentially have considerable impact at an institutional level, it was unclear to what

extent. The situation was complicated by the difficulty of feeding back largely negative results to a range of institutions with vested interests in the system under analysis. Similar concerns regarding the impact of negative findings are pertinent for future plans to present to front line clinical staff as well as the actual participants of the study.

The Interview Process

The interview schedule focused on asking short, open ended and concrete questions about experiences prior, during and after the admission. I became particularly sensitive to feelings engendered by questions about the run up to going into hospital as these were often the most painful and difficult to recount, especially as they came right at the start. In terms of my technique, I focused on creating a relaxed and informal atmosphere, balancing the need to cover all the areas of the schedule with a wish to respond sensitively to individual stories. In other words, it became essential to utilise my clinical skills in managing disclosure. Many service users warmed to this approach and became more able to reflect on their experiences, especially as the interview progressed and their anxieties became more contained. I was pleasantly surprised at the overall success of our engagement considering related problems encountered by previous studies had served to significantly limit the amount of data obtained (Longo, 2002). In other words, learning disabled service users had often been reluctant to speak openly about their experiences to interviewers. I also got the impression it was a very positive experience for the participants with many saying they enjoyed it and asking if they could be of further help in the future.

However, some of the service users did feel shy and anxious, finding the process of the interview difficult. At times they would be unwilling to expand on

points made or would disclose that they felt too shy to answer. This may have been due to the novelty of being asked to reflect on their experiences as well as the length of time taken and lack of clarity surrounding the consent procedure. It may also have been due to prior negative experiences of services and feeling uncomfortable opening up to strangers in front of a tape recorder. I felt it important to pay each service user £10 for their time which acted as both an incentive and recognition of their contribution. I hoped this would ultimately make them feel more empowered, valued and less exploited.

Relatives were often very articulate and clearly valued the experience of talking. It was also apparent that some felt overly burdened, becoming quite emotional in recounting their experiences. Although none wanted to terminate the interview, at times it was necessary for me to clarify boundaries in that we could not offer therapeutic space. Having said that, I felt it important to validate the emotional content and accommodate carers' strong feelings during the interview. Again, this required considerable empathy and encouraged a balance between the schedule of questions and what the person actually wanted to talk about. It was also helpful that most of the interviews with more than one participant were conducted by both researchers. This enabled a research focus to be maintained in the face of complex and difficult material and an opportunity to de-brief afterwards. Along with opportunities provided by my supervisor to reflect on the interview, I felt supported in processing and separating out my own feelings from those of the participants.

Conclusions

Despite the project presenting considerable challenges, the process was overall rewarding and informative. I felt particularly privileged when listening to what were

often personal and touching accounts of very difficult experiences. I was also struck by the shear breadth and depth of the content and feel that in a sense the findings can only ever partly reflect the full meaning of what was said. All parties seemed to gain something from taking part and appreciated someone listening to their experiences, particularly the service users themselves. In fact many often asked if they could be of further help and wanted to know more about the study and its outcome.

Not only did this study underline for me the importance of listening to feedback from inpatients and their families, I also feel it has serious implications for future policy concerning the use of mainstream services for people with learning disabilities. My impression is that policy is sometimes based on ideals. What this study demonstrates is that these ideals are not always reflected in reality. It also suggests that people with learning disabilities are often let down by mainstream mental health inpatient services. Whether the policy is unworkable or not, or whether changes need to happen closer to the point of delivery is a question that hopefully will become clearer over time and with more evidence available.

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National Research Ethics Service (2007). *Section 12: Research involving adults unable to consent for themselves.* REC SOPs: Version 3,4.

APPENDICES

Appendix A1

Main Ethical Approval

NHS
East of England

26 July 2006

Dr Katrina Scior
Lecturer in Psychology
University College London
Sub-Department of Clinical Health Psychology
Gower Street
London WC1E 6BT

Dear Dr Scior

Full title of study:	**Mainstream in-patient mental health care for people with learning disabilities: service user, carer and provider experiences**
REC reference number:	**06/Q0301/34**

Thank you for your letter of 15 June 2006, 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 Chairman.

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.

Ethical review of research sites

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

Conditions of approval

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

Approved documents

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

Document	Version	Date
Application		29 April 2006
Application	Part C	04 May 2006
Investigator CV		29 April 2006

Protocol	4	05 July 2006
Covering Letter		30 April 2006
Letter from Sponsor		26 April 2006
Peer Review		
Interview Schedules/Topic Guides		29 April 2006
Letter of invitation to participant	4	05 July 2006
Participant Information Sheet: Provider version		29 April 2006
Participant Information Sheet: Carer Version	4	11 June 2006
Participant Information Sheet: Service User Non-LD Version	4	11 June 2006
Participant Information Sheet: Service User LD Version	4	11 June 2006
Participant Consent Form: Provider Version	3	10 June 2006
Participant Consent Form: Carer Version	3	10 June 2006
Participant Consent Form: Provider version		29 April 2006
Participant Consent Form: Carer version		29 April 2006
Participant Consent Form: Service User Version	3	10 June 2006
Response to Request for Further Information		15 June 2006
Response to Request for Further Information		15 June 2006
Recruitment Letter	1	05 July 2006
Guide for facilitation of focus groups		29 April 2006
CV for Dr Robin Mutter	2	05 June 2006

Research governance approval

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

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.

Please quote this number on all correspondence

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

Yours sincerely

Chairman

Enclosures: Standard approval conditions
                     Site approval form

Copy to: Dr J Ord
                     Colchester Primary Care Trust
                     659-662 The Crescent
                     Colchester Business Park
                     Colchester CO4 9YQ

                     Carolyn Burden – Tendring PCT

West Essex Local Research Ethics Committee

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

REC reference number:	06/Q0301/34	Issue number:	2	Date of issue:	28 July 2006

Chief Investigator:	Dr Katrina Scior

Full title of study:	Mainstream in-patient mental health care for people with learning disabilities: service user, carer and provider experiences

This study was given a favourable ethical opinion by West Essex Local Research Ethics Committee on 26 July 2006. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.

Principal Investigator	Post	Research site	Site assessor	Date of favourable opinion for this site	Notes [1]
Dr Robin Mutter		North Essex Mental Health Partnership Trust	West Essex Local Research Ethics Committee	26/07/2006	
Dr Robin Mutter	Lecturer in Social Work	Colchester Primary Care NHS Trust	North & Mid Essex Local Research Ethics Committee	26/07/2006	

Approved by the Chair on behalf of the REC:

..... C .... (Signature of ~~Chair/~~Administrator)

(delete as applicable)

.... *LR WRIGHTON* .... (Name)

(1) *The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension of termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.*

Provisional opinion

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.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chairman in consultation with the lead reviewers.

Further information or clarification required

1. A part C of the COREC application form is required for all sites.
2. A brief CV for Robin Mutter is requested.
3. There should be a tick box on the Consent Form for the use of the participant's medical information.
4. The initial consent, taken by the health carer, must be documented. Consent must be taken (and recorded) before the detail is entered onto the form provided as appendix 2.
5. The health carer should do the initial sift of potential participants to lessen the amount of information passed to the researcher. This is also important to ensure that the number of possible participants who are contacted for consent to use medical records but are not then selected for the research interview is minimised – to reduce potential anxiety.
6. The Participant Information Sheet (PIS) states that consent will be renewed at the time of the interview, which would not give sufficient time for the potential participant to decide. However this procedure is contradicted within the protocol; clarification is required. While it is important that consent is renewed by the researcher, sufficient time must be allowed (24 hours or more) before embarking on the research questionnaire.
7. What measures are in place if someone wishes to withdraw consent at the focus groups? Consideration needs to be given on the implications of a late withdrawal of consent on the record of the focus group discussion.
8. Full confidentiality cannot be guaranteed to the focus group participants in cases of untoward revelations. This should be reflected in the PIS.
9. It is suggested that a removable memory stick is used to store all computerised study data and that it is securely locked away.
10. All study data should be kept for 5 years.
11. The PIS should state what will happen to the tape recordings after the study has been completed.
12. The Consent Form must be cross-referenced to the specific PIS.
13. All paperwork must have version numbers and dates.

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

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 20 September 2006.

Ethical review of research sites

After consideration of the research procedures involved in the study, the Committee decided that an assessment should be made locally of the suitability of the investigator, site and facilities ("site-specific assessment"). The lead researcher at each site should be designated as the local Principal Investigator.

You should therefore arrange for Part C of the application form, together with a copy of the local Principal Investigator's curriculum vitae, to be submitted to the Local Research Ethics Committee (LREC) for the site as soon as possible. In the case of research sites outside the

West Essex Local Research Ethics Committee

Attendance at Committee meeting on 18 May 2006

Committee Members:

Name	Profession	Present?	Notes
Mr H Bliss	Lay Member	Yes	
Mr Barry Cole	Educationalist (Vice-Chairman)	Yes	
Dr Qamar Abbas	Associate Specialist in Palliative Medicine	Yes	(Left 17.00)
Dr Alan Calverd PhD	Lay Member	No	
Mrs Carolyn Read	Lay Member	Yes	
Dr Robin Fears	Lay Member	Yes	
Mr Simon Laurence	Lay Member	Yes	
Mr Brian Rayner	Pharmacist (Deputy Vice-Chair)	Yes	
Dr Tuhin Sikdar	Consultant Radiologist	Yes	
Mrs Sarah Starr	Nurse Consultant Critical Care	Yes	(Left 17.00)
Mrs Helen Watkins	Lay Member	Yes	
Ms Vivienne Wright	Teacher/Bereavement Counsellor	Yes	
Mr F Kapasi	Associate Urologist	Yes	(Left 17.00)
Dr Reshma Rasheed	GP	No	

Also in attendance:

Name	Position (or reason for attending)
Mrs Liz Wrighton	Administrator

An advisory committee to Essex Strategic Health Authority

Appendix A2

Site Specific Ethical Approval (SSA)

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Essex 1 Research Ethics Committee
(Note: ESSEX 1 and ESSEX 2 REC's are an amalgamation of
South Essex, North & Mid Essex and West Essex REC's)
Level 9 Terminus House The High
Harlow Essex CM20 1XA

Tel/Fax: 01279 694917
Email: liz.wrighton@eoe.nhs.uk

24 May 2007

Dr Katrina Scior
Lecturer in Psychology
University College London
Sub-Department of Clinical Health Psychology
Gower Street
London WC1E 6BT

Dear Dr Scior

Full title of study:	**Mainstream in-patient mental health care for people with learning disabilities: service user, carer and provider experiences**
REC reference number:	**06/Q0301/34**

The REC gave a favourable ethical opinion to this study on 26 July 2006.

Further notification(s) have been received from local site assessor(s) following site-specific assessment. On behalf of the Committee, I am pleased to confirm the extension of the favourable opinion to the new site(s). I attach an updated version of the site approval form, listing all sites with a favourable ethical opinion to conduct the research.

R&D approval
The Chief Investigator or sponsor should inform the local Principal Investigator at each site of the favourable opinion by sending a copy of this letter and the attached form. The research should not commence at any NHS site until approval from the R&D office for the relevant NHS care organisation has been confirmed.

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.

Yours sincerely

Mrs Liz Wrighton
Committee Co-ordinator

Enclosure: Site approval form

Copy to: Dr J Ord - Colchester Primary Care Trust
                     Carolyn Burden – North East Essex PCT

This Research Ethics Committee is an advisory committee to East of England Strategic Health Authority
*The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England*

Essex 1 Research Ethics Committee

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

REC reference number:	06/Q0301/34	Issue number:	3	Date of issue:	24 May 2007

Chief Investigator:	Dr Katrina Scior

Full title of study:	Mainstream in-patient mental health care for people with learning disabilities: service user, carer and provider experiences

This study was given a favourable ethical opinion by Essex 1 Research Ethics Committee on 26 July 2006. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.

Principal Investigator	Post	Research site	Site assessor	Date of favourable opinion for this site	Notes [1]
Dr Robin Mutter		North Essex Mental Health Partnership Trust	Essex 1 Research Ethics Committee	03/05/2007	
Mr Benjamin Donner	Trainee Clinical Psychologist	Westminster PCT	Riverside Research Ethics Committee	03/05/2007	
Dr Robin Mutter	Lecturer in Social Work	Colchester Primary Care NHS Trust	North & Mid Essex Local Research Ethics Committee	26/07/2006	
Mr Benjamin Donner	Trainee Clinical Psychologist	North London Forensic Service	Barnet, Enfield & Haringey Local Research Ethics Committee	24/05/2007	

Approved by the Chair on behalf of the REC:

.... (Signature of Chair/Co-ordinator)

(delete as applicable)

LIZ WRIGHTON .... (Name)

[1] *The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension of termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.*

Appendix B1

Service User Information and Consent Forms

North East Essex **NHS**
Primary Care Trust

Essex County Council

North Essex **NHS**
Mental Health Partnership
NHS Trust

UCL

Service User Version
Participant Identification Number for this trial:

CONSENT FORM

Title of Project: In-patient mental health care for people with learning disabilities

Researchers: Ben Donner & Katrina Scior

Please tick box

1. I understand what the study is about. I have had the chance to ask questions. I know what I am being asked to do. ☐

2. I understand that my participation is voluntary and that I can stop at any time. I don't have to give a reason if I want to stop. ☐

3. I understand that what I say will be tape recorded. What I say may be shared with other responsible individuals, but they will not be able to identify me. ☐

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

5. I agree to relevant medical information about me being shared with the researchers. ☐

This section to be completed before any participant information is passed to researchers:

_____   _____   _____
Name of Service User   Date   Signature

I confirm that I have passed the Invitation Letter and Participant information sheet to this person and have explained the nature and purpose of the research in a way that I am sure the participant understands.

_____   _____   _____
Health Worker   Date   Signature
Name & Position

This section to be completed at time of interview:

As the researcher I confirm that I have explained the nature and purpose of the research in a way that I am sure the participant understands.

_____   _____   _____
Researcher   Date   Signature

When completed, please pass 1 copy to participant; 1 for researcher file; 1 (original) to be kept in clinical notes

Information to be provided by Healthcare Provider about each Service User Participant

You are advised that you must seek consent from this person before passing any of this information to the researchers! Please see last question on this form and complete Consent Form with the person.

1. Service User's Details:

Name

Current Address & Telephone Number

Age   Sex   M / F

Ethnicity

1a. What is the best way of contacting this person to arrange a meeting?

        Directly by telephone   _____
        Directly by letter   _____
        Via a carer   _____

If 'via a carer', what is their name, role (e.g. mother/ keyworker) and telephone number?

2. What evidence is there that person has a learning disability? (please tick)

        Formal assessment?   _____
        Attendance at Special School?   _____
        Past use of l.d. services?   _____
        Other, please specify_____

        _____

        Or in case of controls, not applicable   _____

3. Does this person have a formal mental health diagnosis?   Yes / No

        If yes, what:

4. To your knowledge are they currently taking psychoactive medication?

        If yes, what and dosage?

5. When was person last admitted for in-patient mental health care?

        Month/ Year

5a. Where were they admitted?

5b. Where were they admitted *from*?
        Home/ Res. Home   _____
        A&E   _____
        Other location, please specify_____

        _____

5c. How long was this admission?

5d. Who was the responsible RMO during the admission?   MH / LD

5e. If person has been discharged when and where to?

5f. If at a different location now, why?

6. Has this person had previous in-patient mental health admissions? Yes/ No

If yes, please state what type of provision and duration of each admission:

7. Is this person likely to be able to take part in a detailed interview about their recent in-patient admission (likely to last between 30 and 60 minutes)?
(i.e. Do they have sufficient verbal skills? Are their mental health problems sufficiently well controlled to allow them to take part?)

Yes / No / Not sure

8. Your details:

Your Name: Your Designation:

Address:

Tel:

e-mail:

9. Has this person given their consent to you passing on this information to the researchers?

Yes   /   No   /   Unsure

If you have answered 'no' or 'unsure' please go back to the person and obtain their consent before passing this information to the researchers. Consent must be formally recorded on enclosed Consent Form and the form must be signed.

10. Carer Details:

We are also looking to talk to each participant's main carer, where this carer has direct experience and views of the inpatient admission (i.e. they did not only take on the care role after the admission). We will talk to the carer jointly with the service user or after interviewing the service user, as the service user wishes.
Is their a main carer who meets this definition?   Yes   /   No

If yes, what is his/ her name and contact details?

Have you informed them about this study? (We are happy to contact them directly.)

Thank you for your help!

North East Essex **NHS**
Primary Care Trust

Essex County Council

North Essex **NHS**
Mental Health Partnership
NHS Trust

UCL

Invitation Letter
Service User LD Version

Name & Address

Date

Dear

We are independent researchers. We have been asked by the local primary care and mental health trusts to find out more about the experiences of people admitted to an inpatient mental health service.

_____, Healthcare Co-ordinator, has suggested we contact you. We are looking to talk to people who have experienced some emotional or mental health problem and were admitted for some in-patient care.

This project is about finding out what people think about their in-patient admission. We want to hear from service users and their carers. We would like to talk to you and your carer about your admission to _____

Please find an information sheet about the project enclosed. We are able to pay you £10 for your time if you choose to take part.

If you decide to take part one of us, Ben Donner, will arrange a time to meet with you. If you are not sure about taking part Ben would be very happy to talk to you more about the project and answer your questions, before you decide. Once you decide to take part, Ben will interview you on your own or with your main carer. You will decide if you want to meet alone or with your carer present. If you decide to talk alone Ben would still like to interview your carer afterwards to hear their views, unless you feel strongly that you do not want this to happen.

If you decide to take part, Ben will contact you and arrange to see you at home or somewhere else you choose.

Thank you for your time!

Yours sincerely

Ben Donner   Katrina Scior
University College London   University College London

Information Sheet

Mainstream in-patient mental health care
for people with learning disabilities:
service user, carer and provider experiences

We are inviting you to take part in this project. We are looking to talk to people who have experienced some emotional or mental health problem and were admitted for some in-patient care. We want to know what people think about the care they receive, what was helpful and what was not so good.

These are some of the questions you may have before you can decide if you want to take part:

What is the aim of this project?
Many people have emotional or mental health problems at times. At times these get so severe that people need some time in a hospital or inpatient unit. At such times it is important that they get support which meets their needs. This project aims to find out what is good about the support people receive and what needs changing. We are asking people to tell us about their experiences.

Why have I been asked to take part?
You have been asked to take part because you spent some time in a hospital or inpatient unit. We are interested what you have to say about this stay.

Do I have to take part?
No, it is up to you.

What will happen if I agree to take part?
The member of staff who suggested you take part in this study will be happy to answer any further questions you have. If you decide to take part you will be asked to sign a form which says you are happy to take part. Ben Donner, the researcher, will then contact you and arrange a time to meet with you (and possibly your carer). Ben will ask you a little what happened just before you were admitted. He will also ask you about your time as an inpatient. If you have left the inpatient place, he will also ask you how things have gone since.

The interview will be tape recorded so that Ben can listen to you properly and remember everything you say.

You are free to stop taking part at any time. You do not have to give a reason for stopping. Stopping will not affect the support you receive.

Will what I say be shared with anyone else?
Nobody else will be allowed to listen to the tape recording of your interview. Ben will write some of the things you say in reports, but he will not say who said these things. Your name will not appear anywhere. The tape recording of your interview will be destroyed once Ben has written down what you said.

What are the potential benefits and risks of taking part?
What you say may help to make things better for other people in the future. Some of the things Ben will ask you about may be upsetting. You do not have to answer questions if you don't want to. If you do become upset Ben will try to help there and then. If you both decide that you need a little more help after the interview Ben will arrange this.

Will I be informed of the outcome of the project?
Yes. At the end you will be sent a brief report saying what we found.

Thank you for reading this. Please ask any questions if you need to.

Appendix B2

Carer Information and Consent Forms

Carer Version
Carer Identification Number for this trial: **UCL**

CONSENT FORM

Title of Project: In-patient mental health care for people with learning disabilities

Researchers: Ben Donner & Katrina Scior

Please tick box

1. I have read and understand the information sheet. I have had the chance to
   consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any ☐
   time, without giving any reason, and without service support for the person in my
   care, myself or our legal rights being affected.

3. I understand that what I say will be tape recorded. What I say may be shared with ☐
   other responsible individuals, but they will not be able to identify me or the person
   in my care.

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

_____   _____   _____
Name of Carer   Date   Signature

_____   _____   _____
Researcher   Date   Signature

When completed pass 1 copy to participant; 1 to be kept for researcher file

This consent form accompanies Invitation Letter and Participant Information Sheet: Carer Version

Colchester **NHS**
Primary Care Trust

North Essex **NHS**
Mental Health Partnership
NHS Trust

Essex County Council

Invitation Letter
Carer Version

UCL

Name & Address

Date

Dear

We are independent researchers who have been asked by the local primary care and mental health trusts to find out more about the experiences of people with learning disabilities admitted to an inpatient mental health service. We want to hear from service users and their carers.

_____ has suggested we contact you. We are looking to talk to individuals with learning disabilities who have experienced some emotional or mental health problem and were admitted for in-patient care. We are also looking to talk to their main carer to hear about their experiences and views about events leading up to the admission, the in-patient stay itself and, where relevant the discharge.

_____ has been asked to participate in this study and if he/ she decides to take part we would also very much like to talk to you. Wherever possible service users and carers will be interviewed separately, but in some cases it may be more appropriate to meet jointly. Interviews with carers will be arranged at a convenient time and venue (usually their home) and will take about 1 hour. The confidentiality of everything service users and carers tell us is assured.

Please find an information sheet about the project enclosed.

If you decide to take part one of us, Ben Donner, will arrange a time to meet with you. If you are not sure about taking part Ben would be very happy to talk to you more about the project and answer your questions, before you decide. Please let _____ know if you are willing to take part or would like to know more. Alternatively you can contact Ben directly on Tel: 07860 404 139 (if I am not available please leave a message clearly stating your name and contact details).

Thank you for your time!

Yours sincerely

Ben Donner   Katrina Scior
University College London   University College London

Carer Version

Information Sheet

**Mainstream in-patient mental health care
for people with learning disabilities:**
service user, carer and provider experiences

We are inviting you to take part in this project. We are looking to talk to people with learning disabilities and their carers about their experiences of in-patient care. We want to know what people think about the care they received, what was helpful and what was not so good.

These are some of the questions you may have before you can decide if you want to take part:

What is the aim of this project?
Many people have emotional or mental health problems at times. At times these get so severe that people need some time in a hospital or inpatient unit. At such times it is important that they get support which meets their needs. This project aims to find out what is good about the support people with learning disabilities and their carers receive at such times and what needs changing.

Why have I been asked to take part?
You have been asked to take part because you are the main carer for someone who spent some time in a hospital or inpatient unit. We are interested what you have to say about this stay, events leading up to it and, if events since they were discharged (if they have left).

Do I have to take part?
No, it is entirely up to you. If you decide to take part you are still free to stop taking part at any time. A decision not to take part or to withdraw from the study will not affect the support you or the person in your care receive from services in future.

What will happen if I agree to take part?
Ben Donner, the researcher, will contact you and arrange a time to meet with you. (He will also talk to the person in your care about their experiences, but is likely to speak to each of you on your own.) He will tell you more about the project and will ask you to sign a form which says you are happy to take part. He will then ask you about events leading up to the admission, your views and experiences of the inpatient stay, and your view on how things have gone since.

The interview will be tape recorded so that Ben can listen to you properly and remember everything you say. Ben will transcribe the interview and will then destroy the tape.

Will what I say be shared with anyone else?
Nobody else will be allowed to listen to the tape recording of your interview. Ben will write some of the things you say in reports, but he will not say who said these things. Your name will not appear anywhere.

What are the potential benefits and risks of taking part?
What you say may help to make things better for other people with learning disabilities and their carers in the future. Some of the things Ben will ask you about may be upsetting. You do not have to answer questions if you don't want to. If you do become upset Ben will try to help there and then. If you both decide that you need a little more support after the interview Ben will arrange this.

Will I be informed of the outcome of the project?
Yes. At the end you will be sent a brief report saying what we found.

Thank you for reading this. Please ask any questions if you need to.

Appendix C1

Service User Interview Schedule

Interview Schedule

1. Setting the Context

At the beginning of the interview it will be ascertained which mental health services have been used. If the participant is able to provide this information the following will be addressed:
- LD and mental health services used at present & in the past
- Number of admissions
- Place of each admission
- Length of admissions
- Care staff/ service providers who service user has had most contact with

At least some of this information will already have been gathered from Health Care Co-ordinators in the process of recruitment and to determine whether the participant meets the study's inclusion criteria. The wording of questions will relate to this information and will be tailored to the circumstances of each participant. Above all these early questions aim at setting the context and focus of the interview, and at augmenting information provided by Health Care Co-ordinators.

2. Events Pre-Admission

I would very much like to hear about your latest admission to X (place of mainstream in-patient admission). Can you tell me what happened so that you were admitted?

Prompts:
What led to the admission?
What was happening for you at the time?

How did others around you respond? What they say? What did they do?
Who thought you needed help?
Did you think you needed help?
What was it like trying to get help?

What staff did you meet before you were admitted?
What did they say to you?
Did you understand what they said?
How did they help?

Were you able to visit X (inpatient place) before you were admitted or did everything happen very fast?

If admitted to same service previously: What did you think about coming back to X?

3. Admission itself

What happened when you were admitted?

Prompts:
Did anyone come with you?
Was it during the day or at night?

Who did you meet when you got there?
What did they say?
Did they explain why you were being admitted?
Did you understand what they said?

Do you remember how you felt?
Did the people you met help you understand what was going on?
Did they help you feel more calm/ less worried?

4. Experiences & Thoughts re. In-patient Stay

Can you tell me about your time at X (place of in-patient admission)?

Ensure the following aspects are covered:
Details of & Treatment
Physical Environment
Relationships with Staff & other Service Users

Prompts: (note use present tense if person still in in-patient care)
What did you think of the place?
Did you have to share a bedroom? If yes, with how many others?
Did you like your room?
Was there anywhere quiet for you to go if you wanted to be alone?

Did anyone come to visit you?
Where did you see any visitors? Was that a nice place or not?
Did you have other contact with Y (usual carer)? Did you talk on the telephone?
Do you think you had enough contact with Y and other people you are close to?

Where did you spend most of your time during the day?
What was that like?
What things did you do during the day?
Was this what you wanted to do?
Were there things you wanted to do but couldn't?

Were you given any medication?
If yes, do you remember what it was called?
What were you told about the medication?
Were you given any written information or pictures about your medication?
Were you told about side effects?
Did you understand what the medication was for?
Do you think the medication helped you?

Did you have meetings with anyone to talk about things/ your worries etc?
Who did you meet with? Did you have a keyworker?Name?
Did talking to them help?

Did you meet with a Doctor?Name?
Did seeing him/ her help? If yes, how did it help?

Did you talk to anyone else about your worries/ problems?
Did that help?

How did you get on with the nurses?
Did they talk to you about your worries/ problems?
Did they understand your worries?
Were they helpful?

How did you get on with the other patients?
Did they talk to you about your worries/ problems?
Did they understand your worries?
Did you make friends with anyone?

Did you have problems with any of the staff or other patients?

What was the food like? Did you have any choice what you ate?

Did you go out while at x?
If yes, where did you go? With whom? How often?
If no, why did you not go out? What do you think about not going out at all?

5. The Discharge

5A: Areas to cover if not yet discharged:

Are there any plans for you to leave x?

Prompts:
Do you know when you will leave?
How do you feel about leaving?
Where will you go to?
Have you visited this place?
Are you getting any help to get ready for leaving?
Who is helping you? What are they doing?
Are people asking you what you want to happen after you leave?
Are they listening to you?

5B: Ares to cover if already discharged:

What happened when you left?

Prompts:
When did you leave?
Did you get any help to get ready for leaving?
Who helped you? What did they do?
Did staff ask how you felt about leaving?
Did they ask you what you wanted to happen after you left?
Did they listen to you?

Where did you move to?
Did you get any help after you left?
Who has been helping you?
What did you do during the day (once you left)?
How did you get on?

What are things like now?
Do you ever think about X?
Do you have nice thoughts or do you worry about having to go back there?
Is anyone helping you make sure you stay well? Who?
How do they help?

Overall, was your time at X helpful or not helpful?
Is there anything that was especially good?
Is there anything that would have made it better?

Is there anything else you would like to tell me about your time at X?

Appendix C2

Carer Interview Schedule

Interview Schedule

1. Setting the Context

At the beginning of the interview it will be ascertained which mental health services X (person they care for) has used. The following will be addressed:
- LD and mental health services used at present & in the past
- Number of admissions
- Place of each admission
- Length of admissions
- Care staff/ service providers who service user and carer has had most contact with

At least some of this information will already have been gathered from Health Care Co-ordinators in the process of recruitment and to determine whether the participant meets the study's inclusion criteria. The wording of questions will relate to this information and will be tailored to the circumstances of each participant. Above all these early questions aim at setting the context and focus of the interview, and at augmenting information provided by Health Care Co-ordinators.

2. Events Pre-Admission

Can you tell me about events that led up to X being admitted to Y (place of in-patient admission)?

Prompts:
Who thought X needed help?
What was it like trying to get help?
Who decided X should be admitted?

What staff from Y did you meet before X was admitted?
What did they say to you and X?
Did you understand what they said?
Did they ask about your concerns?
Did they listen?

Were you able to visit X (inpatient place) before X was admitted or did everything happen very fast?

If admitted to same service previously: What did you think about X going back to Y?

3. Admission itself

What happened during the actual admission?

Prompts:
Who accompanied X?
Was it during the day or at night?

If applicable, who did you and X meet when you got there?
What did they say?
Did they explain why X was being admitted?
Did you understand what they said?
Do you think X understood what they said? If not, why not?

How did X feel at the time? How did you feel?

Did the people you met help both of you understand what was going on?
Did they help both of you feel more calm/ less worried?

4. Experiences & Thoughts re. In-patient Stay

Can you tell me about X's time at Y (place of in-patient admission)?

Ensure the following aspects are covered:
Details of & Treatment
Physical Environment
Relationships with Staff & other Service Users

Prompts: (note use present tense if person still in in-patient care)
What did you think of the place?
Did X share a bedroom? If yes, with how many others?
What did you think of X's room?

Did you visit X there? If not, why not?
Where did you see X when you visited? Was there anywhere pleasant to spend time together?
Did you talk to X on the telephone?
Do you think you had enough contact with X? If not, why not?

What did X do during the day?
What did you think about these activities?
Were there things X wanted to do but couldn't?
Were there things you thought X should be doing (perhaps to get better) but couldn't?

Was X given any medication?
If yes, do you remember what it was called?
What were you and X told about the medication?
Were you and X given any written information about the medication?
Were you and X told about side effects?
Do you think the medication helped?

Did you have meetings with anyone to talk about X's treatment and progress?
Who did you meet with?
Did X have a keyworker?Name?
Did you have regular contact with them? How did this come about?
Did you meet X's doctor?Name?
Were they helpful?

During X's time at Y did you have any particular concerns? These may have been concerns about the future, other family members, yourself etc
Did anyone talk to you about your concerns?
Did you feel they listened and understood your concerns?

How did you and X get on with the nurses?
Did they tell you how X was getting on?
Did you ever raise any concerns with them?
Did you feel they listened and responded to your concerns?

How did X get on with the other patients?
Did X make friends with anyone?

Did X have problems with any of the staff or other patients?
Do you think these were in any way related to him/ her having a LD?

Did X go out while at Y?
If yes, where did X go? With whom? How often?
If no, why did X not go out? What do you think about X not going out at all?

Overall, do you think the staff and doctors at Y understood about X having a LD?
Do you think they understood his/ her needs?
Do you think they were able to meet his needs, at least some of the time?

5. The Discharge

5A: Areas to cover if not yet discharged:

Can you tell me about plans for X to leave Y?

Prompts:
Do you know when X is due to leave?
How do you feel about X being discharged?
Where will X go?
Have you and X visited this place?
Are you and X getting any help to get ready for him/ her leaving?
Who is helping you? What are they doing?
Are people asking you about your concerns about the future?
Do you feel they listen and understand your concerns?

5B: Areas to cover if already discharged:

Can you tell me what happened when X left Y?

Prompts:
When did X leave?
Did X get any help to get ready for leaving?
Who helped X and what did they do?
Did staff ask X how he/ she felt about leaving?
Did they ask X about his/ her hopes for the future?
Did they listen to X?
Did staff ask you how you felt about X leaving?
Did they ask you about hopes and concerns for the future?
Did you feel they listened to you?

Where did X move to?
Did you and X get any help after the discharge?
How has X been getting on since being discharged?
What has X been doing during the day?
What have things been like for you since X was discharged?

What are things like now?
Do X ever talk about Y?
Does he/ she have nice memories or does he/ she worry about having to go back there?
Who is offering support to you and X now? Is that helpful?

Overall, do you think the admission and X's time at Y was helpful or unhelpful?
Is there anything you'd single out as particularly helpful?
Is there anything that would have made it more helpful, both for X and for you?

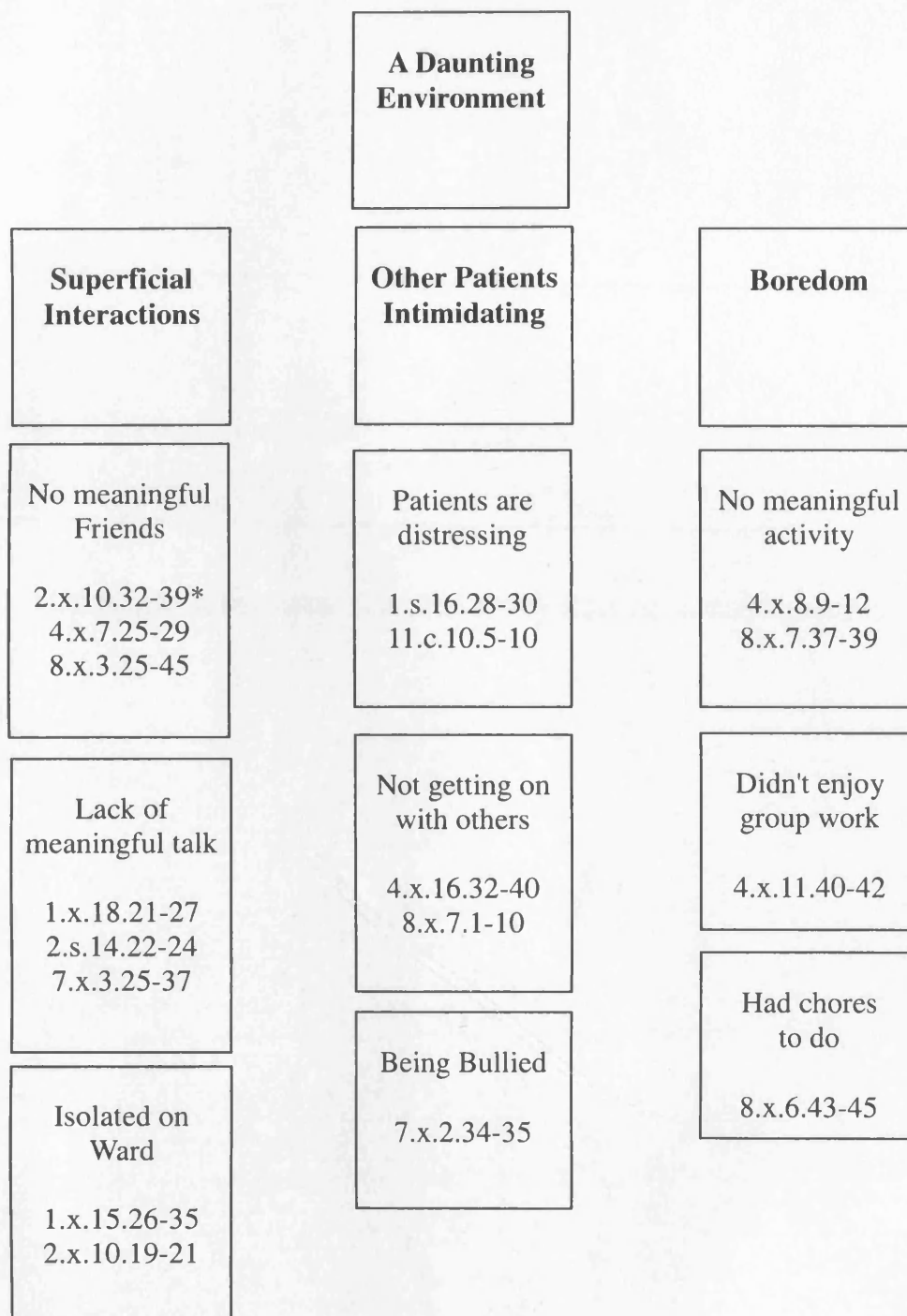Is there anything else you would like to tell me about X's time at Y?

Appendix D1

Steps of the Analysis

Example of stage 1. Initial thoughts and stage 2. Identification of themes: Extract from Case 1, Interview 1.

Stage 1. Initial Thoughts		Stage 2. Identification of Themes
	I. So how long does that take?	
Impact on carer – shoulders responsibility Helpless and left by services Paranoid	C. Oh blimey it could take hours hours as umm it's not a priority case then your sitting in the waiting room umm like she's rambling on swaying saying she doesn't want to be here and you have to really watch her all the time. It makes me feel how can I describe it. It makes me feel like im helpless. Im almost paranoid cos im thinking of other people looking at me, watching her and you know X's swaying back and forth and things like that. And that's what I feel.	Carer feels helpless
Problems with access due to LD. Leads to a longer process of admission	S. And then when the mental health team come down and do there assessment, once they've done that they then sometimes because she has a learning disability wont agree that its her mental health problem that is the problem and that's the one that needs the treatment so then we have this crisis meeting C. Yeah yeah	Having an LD leads to more barriers at access to MH services.
Disputes or battles between services at the expense of care for X	S. Where your sitting there with the mental health nurse and the community LD nurse from whatever team discussing who should be the one dealing with it. I. Is that a common occurrence? C. Yes	Battles between services
Constant and always happens	S. Everytime C. Everytime	Access problems every time
Constant problem and for others too Sent home on leave without adequate care	S. Everytime someone gets admitted we have this problem C. Not last year but I think the year before when X got admitted umm they sent her home for a weekend and they actually had to send out not doctors but two nurses to come and see X…to see how she was and that didn't last long if at all…a couple of days and then that was it, back in then.	

Example of stage 3. Clustering of Themes: Extract from wall surface paper exercise

	A Daunting Environment	
Superficial Interactions	**Other Patients Intimidating**	**Boredom**
No meaningful Friends 2.x.10.32-39* 4.x.7.25-29 8.x.3.25-45	Patients are distressing 1.s.16.28-30 11.c.10.5-10	No meaningful activity 4.x.8.9-12 8.x.7.37-39
Lack of meaningful talk 1.x.18.21-27 2.s.14.22-24 7.x.3.25-37	Not getting on with others 4.x.16.32-40 8.x.7.1-10	Didn't enjoy group work 4.x.11.40-42
Isolated on Ward 1.x.15.26-35 2.x.10.19-21	Being Bullied 7.x.2.34-35	Had chores to do 8.x.6.43-45

The reference should be read as follows, case number, participant (X=service user, C=carer and S=paid carer), page number and line numbers.