

# SERVICE USER INVOLVEMENT IN REDCAR AND CLEVELAND'S MENTAL HEALTH SERVICES

AN EVALUATION OF THE LEVEL OF SERVICE USER INVOLVEMENT IN THE  
REDCAR AND CLEVELAND LOCALITY WITH AN EXPLORATION OF  
FACTORS CONSTRAINING PROGRESS AND HOW THESE MIGHT BE  
OVERCOME

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## **ABSTRACT**

Service user involvement has become one of the cornerstones of Governmental policy in regard to the National Health Service, being enshrined in the Health and Social Care Act 2001. This study examines the growth of user involvement in mental health services nationally, by reviewing recent academic literature on the subject. It then utilises a case study approach to explore how user involvement is developing in Redcar and Cleveland's mental health services. Qualitative methods, combining interviews and focus groups with both service users and professionals provide the main data for the study, in an attempt to access the meanings which individual users attach to their involvement as well as the progress being made.

Barriers to involvement are explored, as are possible means of addressing constraints identified. The study highlights the importance of users receiving feedback from their involvement and of it being relevant to their own experience. Indications are that constraints to involvement in the locality tend to cluster around organisational issues and a series of recommendations are put forward to resolve these and other inhibiting factors.

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## GLOSSARY

CPA	Care Programme Approach
CHI	Commission for Health Improvement
DOH	Department of Health
LDP	Local Delivery Plan
LIT	Local Implementation Team
MDT	Multi-Disciplinary Team
MHM	Mental Health Matters
NHS	National Health Service
NRF	Neighbourhood Renewal Fund
NSF	National Service Framework
PCT	Primary Care Trust
SSD	Social Services Department
STAMP	South Tees Advocacy in Mental Health
STR	Support, Time, Recovery (worker)
TNEY	Tees and North East Yorkshire (NHS Trust)

## **CHAPTER ONE. INTRODUCTION AND BACKGROUND**

Traditionally, mental health care provision in the UK has been based on a paternalistic model dominated by the expertise of the professional over the passive recipients of its services or 'patients'. The past decade has witnessed a change in this relationship with a new emphasis developing on the patient as 'consumer', a change which will be explored throughout this study. Patient empowerment is at the heart of New Labour's vision for Health and Social Care and the concern with social exclusion underlines the view that mental health service users<sup>1</sup> are citizens with the same political, civil and social rights as any others.

The Government has developed a Modernisation Agenda for Mental Health which is enshrined in the National Service Framework (NSF) for Mental Health (1999). At local level this is taken forward by the work of the Local Implementation Team (LIT), which will be described more fully later in this chapter. An Implementation Guide and a range of performance indicators prescribe the services which each Locality must develop and progress against these targets is reviewed annually in the Autumn Review. User involvement in services is one such target, with performance indicators concerning 'meaningful' involvement and user-run services. The research set out here was designed to inform that development work.

### **1.1 Research Aims and Objectives**

#### **1.1.1 Overall Aim**

To determine how developed the levels of service user involvement are in mental health services, and to examine factors constraining progress and how these might be overcome.

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<sup>1</sup> In this dissertation the term service user is employed to cover any person who uses or has used mental health services. The term has been chosen by the author as it appears to be the most widely used and neutral of the alternatives. Other possible terms are 'survivor', 'pioneer' and 'service consumer'.

### **1.1.2 Specific Objectives**

1. To produce an up-to-date review of the literature relating to mental health service user involvement in the UK, in order to identify existing knowledge and build upon it.
2. To explore the meanings which service users and professionals attach to the notion of 'service user involvement'.
3. To examine the levels of user involvement in the care planning process; the delivery of mental health services and the planning of such services in Redcar & Cleveland and to map the results against a matrix drawn from acknowledged good practice.
4. To identify any factors which might be affecting implementation levels.
5. To consider ways of overcoming any such constraints and to convey these findings to both service users and professionals to assist in improving levels of involvement.

### **1.2 Rationale**

Mental Health Service user involvement is a statutory requirement upon the NHS and Social Services Departments. It is enshrined in legislation (The NHS & Community Care Act 1990; The Health and Social Care Act 2001), and crucially in the National Service Framework (NSF) for Mental Health 1999. The development of 'meaningful service user involvement' is one of the NSF performance indicators against which each service delivery Locality is judged annually by the Department of Health, although 'meaningful involvement' is not defined.

The Redcar & Cleveland Local Implementation Team (LIT) for the NSF has consequently commissioned this piece of research to enable them to best decide how to develop user involvement further. Findings will also be shared with local user groups.

A literature review of the subject indicated that there are a number of potential constraints to involvement operating at different levels; individual, organisational

and societal, and if local constraining factors are identified, they can accordingly be addressed.

As meaningful involvement has not been officially defined (although there are plenty of unofficial 'good practice' guides), it would be helpful to have a local interpretation of the concept in order to reach a local solution.

### **1.3 Theoretical Underpinning**

This study is firmly grounded in the traditions of public engagement theory and uses the analytical tools, e.g. 'ladders of participation' (Arnstein (1969)), which have been developed within that tradition. Theorists tend to favour either a view of the service user as a consumer or as a citizen. The consumerist view is typified by the Conservative Government of the 1980s, who encouraged the use of business practices and 'consumer solutions' in public sector management. Consumer theorists advocate public consultation about pre-defined services in order to respond to the needs of the consumers (Kelly 1999). At the same time as the politicians were advocating a customer orientation in public services, service user movements in areas such as mental health were taking this further and viewed services users as citizens with the civil, political and social/economic rights associated with that status (NIMHE 2003; Hickey & Kipping 2003; Harrison & Mort 1998; Corrigan & Joyce 1997). This research will adopt the approach of Barnes & Shardlow (1997) who argue that public sector service users are both consumers **and** citizens and enhanced citizenship is the goal of the socially excluded users of mental health services, a status which can develop beyond merely being consulted about services.

Several public engagement theorists have developed analytical models to gauge levels of user involvement in services. Notable amongst these is Arnstein's (1969) 'ladder of participation' which delineates a spectrum of involvement ranging from being manipulated by the provider, through consultation to partnership and ultimately to citizen control. More recent writers in the field of mental health service user involvement have developed matrices to map involvement levels (Hoggett 1992; Peck et al. 2002). This research employs a

matrix adapted from the work of Peck et al. in order to map the findings regarding levels and types of user involvement in Redcar & Cleveland. (See below)

**Fig. 1.1 Involvement Matrix**

<b>Area of Involvement</b>	<b>Levels of Involvement</b>		
	<i>Receives information</i>	<i>Consulted</i>	<i>Agent in Control</i>
<i>Care Co-Ordination</i>	Receives care plan	Agrees care plan	Direct Payments
<i>Delivery of Services</i>	Receives information re. services	User surveys	User-run services
<i>Planning of Services</i>	Receives community care plans	Represented on LIT	User – run LIT

Some boundaries may overlap and so boxes will contain several types of involvement. Peck et al. (2002) argue that

"A Locality committed to user empowerment would have activity in most cells in the matrix in order to reflect both the range of the engagement that could be chosen by service users and the potential movement of users between strategies." (op. cit. 2002 pp 444-5)

#### **1.4 Organisational Background**

Before considering user involvement in more depth, it will be helpful to have an overview of the organisational context in which mental health services are delivered in the Redcar and Cleveland Locality.

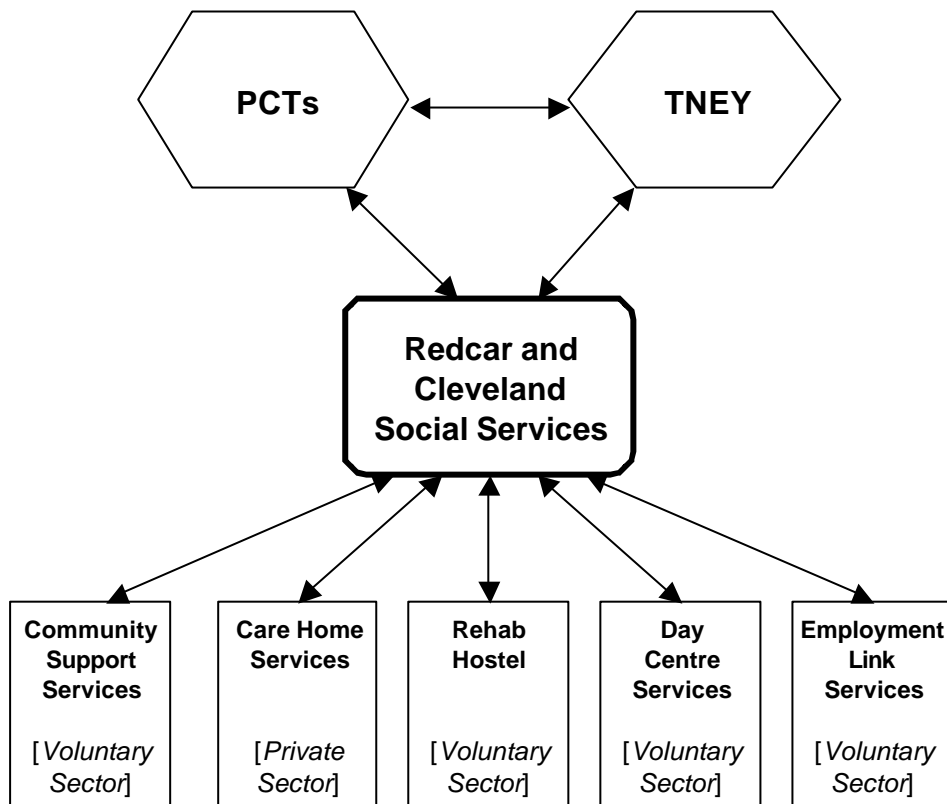
Mental health is one of the key areas of public service provision where partnership working is a requirement, because of the complexity of the social problems involved.

In the Redcar and Cleveland Locality (which is coterminous with the eponymous Local Authority) mental health services are provided by means of partnerships between Health, Social Services and the private and voluntary sectors. Tees and North East Yorkshire NHS Trust (TNEY) **provide** in-patient and community mental health services; Langbaugh and Middlesbrough Primary Care Trusts (PCTs) are the key NHS **purchasing** bodies (the Locality boundary is not coterminous with the PCT boundaries); and Redcar and Cleveland Borough

Council Social Services who **purchase** care home, day centre, community support and employment services via contracts with the private and voluntary sectors and **provide** social work and community support services.

This is best illustrated diagrammatically; (Fig. 1.2)

**Fig 1.2 Organisational Partnerships in Redcar and Cleveland**



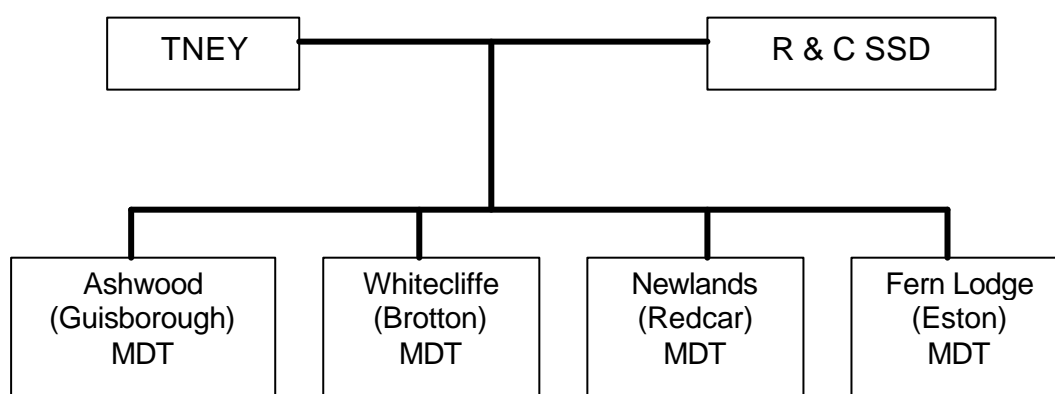
This diagram simplifies somewhat the true complexity of partnership working, as the partnership organisations all work with each other and with their service users and carers to plan and deliver care. This comprehensive partnership working is epitomised by the Local Implementation Team (LIT) which oversees the implementation of the National Service Framework for Mental Health (NSF) in the Locality and involves representatives from the entire partnership.

A further factor to be borne in mind is that, as the name implies, TNEY provide mental health services to five other Localities as well as Redcar and Cleveland, so reference to 'Teeswide' initiatives reflect this responsibility.

It will be helpful to outline some of the specific services and providers in the Locality, in order to clarify the following study .

Care Co-ordination, which is the assessment and care planning process in mental health, is delivered by multi-disciplinary teams (MDTs) based in 4 Resource Centres in each of 4 geographical sectors of the Locality. A typical MDT will comprise one consultant Psychiatrist, possibly a staff grade psychiatrist or a senior House Officer, two social workers, two or more Community Psychiatric Nurses, one or two centre-based nurses, an Occupational Therapist, a Home Treatment worker, an Assertive Outreach worker and various community support staff. Service users receive their care from their local Resource Centre as illustrated below. (Fig. 1.3)

**Fig. 1.3 Mental Health Resource Centres**



The voluntary sector provide a range of community-based services in the Locality as follows (Fig. 1.4);

**Fig. 1.4 Contracted Community Services**

<b>Creative Support</b>	<b>Mental Health Matters</b>	<b>Redcar &amp; Cleveland MIND</b>
Rehabilitation hostel	Drop-in day service at The Grange, Eston	Drop-in day services in Redcar and East Cleveland
Outreach support services	Employment Services	Mental Health Information Service
Dual Diagnosis support service	Host organisation for Service User Development Worker	

It should be noted that service users who access drop-in day services tend to use the day centre in their sector, although all service users are welcome to attend any of the contracted day services as they wish.

Private sector companies also provide residential and nursing home care for people with mental health problems, which can be accessed privately or via Health and Social Services for public funding. Partnership links are less strong with these companies, although they are invited to send representatives to a quarterly Community Resources Forum.

A service user group exists in the Locality which is known as 'Greenlights' (taken from the traffic-light self assessment system which the LIT is required to adopt by the Department of Health). It has been in existence for under two years and is intended as a Locality-wide group, which is currently facilitated by the Service User Development Worker who is based at the Grange but answerable to a sub-group of the LIT. The group meets monthly and attracts around twenty people per meeting. Greenlights send representatives to LIT meetings and other planning groups across the Locality.

The partner organisations in Fig. 1.2 have all committed themselves to user involvement not only via the LIT, but through their own written policies and Business Plans. This study looks at the progress which the partnership has made towards this goal and what remains to be achieved. There follows a review of the recent literature on the subject of user involvement in mental health services in the UK, which has provided the springboard for the structure of the research.

## **CHAPTER 2 A LITERATURE REVIEW OF USER INVOLVEMENT IN MENTAL HEALTH SERVICES IN THE UK.**

### Keywords

User involvement; mental health services UK; patient participation; user empowerment; consumer participation; user engagement.

### Databases Used

ASSIA; Ingenta; Emerald; CINAHL; Medline.

### Websites Consulted

MIND; Sainsbury Centre for Mental Health; The Mental Health Foundation; Joseph Rowntree Foundation; Department of Health; Local Government Association; Commission for Patient and Public Involvement in Health; Scottish Development Centre for Mental Health; Audit Commission; National Schizophrenia Fellowship.

## **2.1 Introduction**

User involvement in mental health services has become a statutory obligation under New Labour, as indicated in Chapter One, and in the past five years the subject has been the focus of a great deal of academic and other literature. From this literature some key themes emerge, which will be examined in this review. Firstly, the origins of the service user involvement in the public service consumerism of the 1990s and the civil rights movement from the 1960s onwards will be considered. In this context the literature regarding citizenship and mental illness will be examined.

A consideration of how service user involvement is enshrined in policy documents and the legislative framework follows, followed by a review of the literature about what constitutes 'involvement' and why it is regarded as important. Reference is made to the increasing number of guidance manuals for those attempting to involve users in services. The literature relating to successful service user involvement, barriers to involvement and how to overcome them, and the effects of involvement, are then be evaluated. Finally a conclusion is reached in which current research is summarised and the way forward is considered.

In compiling this review the main emphasis has been on recent academic journal articles relating to service user involvement in the UK.

## **2.2 Background to Service User Involvement**

Until the 1960s, psychiatric patients were usually hidden from view in secluded hospitals, where they enjoyed few outside contacts. This was allegedly 'therapeutic' for the mentally ill and protected the rest of society from the 'mad' (Barnes and Bowl 2001). The development of psychotropic drug treatment regimes for mental illness meant that fewer patients needed long term care in hospital and 'care in the community' was the approach favoured by successive governments, eager to cut public spending.

Welfare provision generally continued to be paternalistic until the 1980s with professionals seen as authoritative experts to whom the individual with a problem deferred. (NIMHE 2003) This has begun to change and the literature indicates that there are two separate but related developments which account for this; the growth of consumerism in public service orientation and the development of campaigning service user groups with an emphasis on civil rights (NIMHE 2003; Peck et al. 2002; Truman & Raine 2002; Barnes & Bowl 2001).

The development of a consumer orientation in public service provision began in the 1980s with the Conservative Government encouraging the use of business practices to transform the public sector. The idea was that 'consumers' of services could exercise choice in deciding upon a particular service and it was encouraged by the NHS & Community Care Act (1990) which split the purchaser and provider functions in health and social care services (Hickey & Kipping 2003). The use of 'consumer solutions' such as public consultation and complaints procedures were introduced. This involves a change in the user/provider relationship i.e.

"the passive dependant recipient of services is replaced by...the consumer with 'demands' as well as needs that must be responded to" (Kelly 1999 p137)

However,

"The citizens were to be empowered as individual consumers with the ability to choose and complain - not the ability to proactively shape services" (Corrigan & Joyce 1997 p419).

Contemporaneously, the service user movements such as Survivors Speak Out and the National Schizophrenia Fellowship, whilst welcoming more responsive services, have tended to approach user involvement from the position that service users are also citizens with as equal rights as any others (NIMHE 2003; Hickey & Kipping 2003; Harrison & Mort 1998; Corrigan & Joyce 1997). Barnes & Shardlow (1997) argue that in the public sector, service users are both consumers and citizens and that the two are not opposed, but that it is through enhanced citizenship that users become empowered rather than merely being consulted about pre-defined services. The concept of the 'citizen' is the subject of debate (Barnes & Shardlow 1997; Pierre 2000), although it is widely agreed that citizenship confers civil, political and social/economic rights. Of crucial importance to socially excluded groups such as the mentally ill is the extent to which these rights can be realised and the constraints upon this (Pierre 2000; Harrison & Mort 1998).

### **2.3 The Statutory Framework**

As mentioned earlier, the NHS & Community Care Act 1990 stated that service users and carers must be involved in local planning and consequent research has shown that there followed a proliferation of service user groups who are actively engaged in consulting with decision - making bodies (Wallcraft et al. 2003).

Almost all subsequent mental health policy documents and legislation have emphasised the need for user consultation and involvement. The NHS Plan 2000 is concerned with the development of a patient-centred NHS and this was followed up by the Health and Social Care Act 2001 which places a duty on health service bodies to involve and consult patients and the public about service planning, development and decision-making. The Government has not prescribed what form this involvement should take, but it has developed some 'toolkits' for public involvement. (DOH 2001; Audit Commission 1999)

Perhaps most crucially, the National Service Framework for Mental Health 1999 sets national standards for mental health service, which service users were involved in developing. It is also expected that service users will be involved in the planning and delivery of care. The development of 'meaningful service user involvement' is one of the performance indicators against which each locality is judged annually, although there is no clear outline of what constitutes 'meaningful' involvement.

## **2.4 The Concept of User Involvement and Why it is Important**

The concept of involvement is ill-defined in the literature, with some writers dismissing consultation as not being involvement at all (Simpson et al. 2002; Harrison and Mort 1998). Several writers employ helpful 'ideal type' models of participation developed from public engagement theory (Hoggett 1992; Hickey & Kipping 1998; Peck et al. 2002). Using such models it will be possible to evaluate the level of user involvement in any service and indicate to providers how this can be improved upon.

Hickey & Kipping (1998) develop a simple participation continuum from 'information/explanation', followed by 'consultation' (which they associate with the consumerist approach) through to 'partnership' and 'user control' (which they argue reflects the democratisation approach as a power shift is involved). This is similar to Arnstein's (1969) much earlier 'ladder of participation', which is discussed in Chapter 4.

More complex matrices are developed by Hoggett (1992) and Peck et al. (2002). Hoggett's model distinguishes between whether the user is involved as an individual or collectively and how much participation and control they have. Peck et al. devise a more complex model which has three types of involvement and four levels at which each might take place.

Generally the literature reflects the view that service user involvement in mental health is a desirable activity, not just for its own sake as a basic right (Corrigan & Joyce 1997) but with the intention that it will result in useful changes at an individual user level as well as in the provision of services.

The benefits of service user involvement at a service provision level stem from the view of service users as experts in their own experiences of mental disorder

and the mental health services they are offered (NIMHE 2003). Their priorities are often at odds with the mental health professionals with whom they work e.g. service users tend to cite poverty, employment and sustaining relationships as their main concerns, compared to service integration and new management styles which preoccupy the professionals (Barnes & Bowl 2001; Lindow 1999).

User involvement is thought by some writers to force professionals to re-evaluate their own approach. The National Schizophrenia Fellowship (1997) states that user involvement should lead to improved partnership working; better understanding by professionals of the impact of mental illness on users; better targeting of services with a knowledge of what interventions are most effective; improved working relationships and increased compliance with treatment and care plans by users. They also claim that at an individual level the service user is likely to feel empowered by being listened to and valued. This individual 'therapeutic' effect is hard to measure and often the unintended if welcome consequence of user involvement, but as Barnes & Bowl (2001) warn, "user involvement is not a clinical intervention technique." (p95).

## **2.5 Constraints to User Involvement**

Much of the literature on this subject concentrates on the constraints to user involvement as a result of a general perception that despite government initiatives and the user movement itself, slow and patchy progress is being made. (Campbell 2001; Bowl 1996; Peck et al. 2002). Such constraints operate at many levels, from individual user level, through organisations, professions and the wider society (Hickey & Kipping 1998).

At an individual level, it is acknowledged by some writers that some service users, due to characteristics related to their illness, age, gender or educational background, will not want to become involved in shaping the services they receive (Hickey & Kipping 1998). Others may have internalised the bio-medical model to an extent that their personal agency is invalidated (Pilgrim & Waldron 1998). However for those who do want to become involved there may exist individual constraints such as being detained under the Mental Health Act . This is an experience which can be intensely disempowering (NIMHE 2003) in that the patient's wishes are often largely discounted 'in their best interests'.

Most of the literature concentrates on the organisational barriers to involvement as it is widely agreed that it is at this level that they mostly operate. (Hickey & Kipping 1998; NIMHE 2003; Bowl 1996). Organisational barriers include a lack of information for service users about their illness, types of treatment, prognosis, the law, services etc. (NIMHE 2003; Joseph Rowntree Foundation 2003; Crawford 2001). Without such information, users are unable to make informed choices.

“The key point here is that, in many circumstances, service users cannot achieve the outcomes they want if they are not aware of the services that are there to support them and that such a lack of information will often lead to low expectations of the outcomes that can be achieved.” (Joseph Rowntree Foundation 2003 p13)

Commitment to user involvement at organisational level must be a ‘core value’ rather than a ‘bolt on’ (Hickey & Kipping 1998) as it is expensive and time consuming (NIMHE 2003; Ryan & Bamber 2002). Service users can often feel intimidated by involvement in meetings where there is an expectation that everyone is equally knowledgeable and meetings are commonplace. It may prove prohibitatively costly for users to attend meetings and the meetings may be held in places which the service users associate with stigma and coercion e.g. a psychiatric hospital. As Viv Lindow writes

“at my first experience of user involvement, I arrived at the meeting exactly on time, and there was only one place left at the table. This was next to the consultant psychiatrist who had given me ECT, I didn’t say anything for several meetings. The second group I joined involved travelling to London. I was very poor and lacking in confidence and wondered whether I could go, even wearing my best sweater. When I got there, among the group were three Professors, two Lords, a Bishop and me, the only service user. I got going at the end of the third meeting, but never felt confident enough to say what a disadvantage I was trying to work under.” (Campbell & Lindow p6)

One of the most crucial constraints on involvement is the resistance of mental health professionals to user empowerment (Harrison & Mort 1998; Summers 2003; Pilgrim & Waldron 1998). Whilst these studies show a positive view of user involvement on the part of professionals, there appears to be a difference between expressed views and practice (Bowl 1996; Summers 2003; Campbell 2001) although Bowl (1996) finds that the professionals are not necessarily aware of this. Some professionals are dismissive of the contributions of service

users, on the grounds that they are inappropriately expressed (Crawford 2001). Psychiatrists attitudes are seen as having as important influence on the implementation and impact of user involvement (Summers 2003). This often operates through

“subtle, self-reinforcing processes, where ‘experts’ power is based on knowledge assumed objective even when others disagree. Users’ input is then easily diluted, adapted or redefined in professionals’ terms or seen as valid only when it is acceptable, and real differences in agendas and power may be obscured.” (Summers 2003 p172).

Harrison & Mort (1998) suggest that under these circumstances, user involvement becomes a ‘technology of legitimation’ for the decisions and activities of NHS and social care agencies.

The most frequently expressed concern of professionals is about the ‘representativeness’ of the individual service users who become involved in shaping services (Crawford 2001; Bowl 1996; Harrison & Mort 1998; NIMHE 2003). Such concerns involve the view that the articulate, interested service users do not represent the ‘typical’ user. This has led to some user representatives questioning their own representativeness, having been made to justify their position in this way (Bowl 1996). However, ‘representativeness’ is an issue for those representing any group e.g. doctors (Crawford 2001) and may be used as “A subconscious method of resisting user involvement” (NIMHE 2003 p7) and as such represents a ‘double standard’.

Finally, constraints exist at a societal level in the general attitude towards the mentally ill.(Truman & Raine 2002; Hickey & Kipping 1998)

“Typically they may be seen as irrational, impulsive and generally lacking in the necessary attributes for sensible decision making...At worst they may be perceived as ‘dangerous lunatics’ from whom the public need protecting (a view not discouraged by certain sections of the media)” (Truman & Raine p142)

## **2.6 Keys to Overcoming Constraints to User Involvement**

A number of authors, both from academia and from a user movement perspective, have recognised that user involvement is subject to constraints and

have concerned themselves with addressing this issue (Simpson et al. 2003; Wallcraft et al. 2003; Scottish Development Centre for Mental Health 2001; MIND 2003; National Schizophrenia Fellowship 1997; NIMHE 2003).

The issue of citizen engagement in general has also been addressed by the Audit Commission (1999; 2003). On a broad level the Audit Commission identify five critical factors that work together to ensure that public bodies successfully engage with users and citizens. These are: commitment to user focus; understanding your communities; clarity of purpose; communicating appropriately; and delivering change (Audit Commission 2003 p4).

Whilst these principles are all very commendable, the underlying premise of the Audit Commission's approach is that engagement equals consultation and it is something which is done **by** public bodies **to** service users. It is clear from the literature that user/survivor groups do not feel that this takes involvement far enough up the 'participation ladder' for them. MIND are campaigning for a clear shift in power in favour of users. It would seem that this remains a contentious area.

The literature identifies a number of methods of enhancing user involvement. Firstly, by the provision of information to mental health service users regarding treatment options and possible side effects; how to complain and access noted; and how to get involved in planning, managing and monitoring services (MIND 2003). Individual professionals must adapt their way of thinking so that they acknowledge the expertise of users (National Schizophrenia Fellowship 1997) and treat them as equals who have developed strategies for living with their illness (NIMHE 2003). Workers should focus on the users' strengths and resources.

Organisations need to address the practical barriers to involvement (National Schizophrenia Fellowship 1997; Bowl 1996) such as the choice of meeting venues and times; meeting out of pocket expenses incurred by users (Ryan & Bamber 2002); pre-meeting support and issuing agendas early; support during meetings if distressed; avoiding the use of jargon; providing secretarial support etc.

Much of the literature stresses the need for the routine involvement of service users in all aspects of planning, monitoring and development of mental health services (NIMHE 2003; National Schizophrenia Fellowship 1997; Campbell 2001). For example the involvement of service users in the training of professionals is seen as essential (National Schizophrenia Fellowship 1997; Bowl 1996) and whilst this is happening, as Campbell (2001) points out, there is a dearth of research on how it is developing. The NSF argues for users to be involved in commissioning and conducting research, staff selection and employment as mental health workers. In other words

“services need to be based on an explicit commitment to genuine partnerships between users and professionals.” (NIMHE p9)

## **2.7 Evaluating Examples of Service User Involvement**

There are several studies in the literature of individual, localised mental health initiatives which are involving service users (Perkins et al. 1997; Pilgrim & Waldron 1998; Bailey 1997; Peck et al. 2002; Hostick 1998; Barnes et al. 2000; Truman & Raine 2002), from which valuable lessons can be learned for those implementing similar projects. Truman & Raine’s (2002) study of mental health service user involvement in running a community gym in Barrow highlighted the use of contracts for user volunteers to clarify roles, and the importance of flexible degrees of participation to match the pace and personal resources of the individual. Peck et al.’s (2002) research into levels of user involvement in Somerset’s mental health services underlines the tendency noted earlier for the long-established patterns of staff behaviour proving resistive to change and that care plans are still often decided without serious input from users. Crucial to changing this was the relationship between the user and the individual staff member. Perkins et al. (1997) studied the employment of service users as mental health professionals in inner London and concluded that

“ the employment of a few service users in existing services does not fundamentally change their nature. What it may do is to provide some much needed employment, render mainstream services somewhat more sensitive to the needs of their users, and change the attitude of some mental health workers.” (Perkins et al. p318)

However, research by Lindow & Rooke-Matthews (1998) found that service users who had been employed in this way experienced discrimination from management, such as being seen as 'vulnerable' or of 'over-identifying with clients' or just not promoted. They themselves felt that their experiences of mental ill-health were of great value in their work.

These small studies provide insights and are likely to be useful in local mental health service development, but little research has been undertaken on a national level on this subject. Robert et al. (2003) have undertaken a larger study of six NHS Trust areas who had joined to form a 'Mental Health Collaborative'. They found relatively unimaginative and tokenistic involvement of service users at the outset of the Collaborative, but this developed significantly and the lessons learned included the usefulness of involving users in mapping the patient journey; the importance of involving users in questionnaire design if service users views are to be sought; having more than one service user representative on any project team to provide mutual support and enhance confidence; and the importance of payment and training for users who become involved in projects.

Simpson & House (2002) undertook a review of the international research into involving users in the delivery or evaluation of mental health services and identified five randomised controlled trials and seven other comparative studies. They found that payments, training and support for users were available in nearly all cases. Despite identifying 'substantial methodological weaknesses' in most of the studies, they concluded that service user involvement is unlikely to damage the users and that there were benefits to using service users as employees, trainers and researchers.

## **2.8 Conclusion.**

From being a subject close to the heart of mental health service user groups but little researched in academic circles, user involvement has become the focus of a plethora of academic writing in the last five years, as a result of the forceful push it is receiving as a policy goal in New Labour's Modernisation Agenda. The most useful writing grounds research into user involvement firmly in public engagement theory, viewing users as citizens as well as users of services. In this way it is possible to assess the progress of user involvement in any given organisation or

locality by measuring it against some sort of 'participation matrix'. Whilst several small scale studies have been undertaken in this area, there is now a need for more systematic review of the progress towards involvement, at both local and national levels. A clearer notion of what constitutes best practice in this area needs to be developed.

It is clear from the literature that professionals have a crucial role in the success of user involvement, both in terms of the support and time they are prepared to allocate to it as well as in their underlying attitudes. Indeed, both academics and user groups alike identify societal attitudes to mental illness as the main barrier to further meaningful service user involvement. The user movement is currently engaged in fighting discrimination and social exclusion and is forming alliances with other disadvantaged groups. It is to enhanced citizenship that they aspire, which includes involvement in mental health services, but also looks beyond.

## **CHAPTER 3 METHODOLOGY**

### **3.1 Overview**

The research took the form of a case study of the involvement of users in the Mental Health Services in Redcar & Cleveland, which as outlined in Chapter One, are provided in partnership between the statutory and voluntary sectors.

The methods employed are mostly qualitative, although some available but previously unanalysed secondary data were examined. Whilst the researcher is an advocate of service user involvement and hopes the findings of the work will be used to improve levels of involvement locally, it should be emphasised that this is not 'action research', as espoused by Reason & Bradbury (2001).

Qualitative methods were selected as the most appropriate, as it was the intention to explore the meanings which individuals attach to user involvement and it allows for more flexibility of participant responses. A phenomenological approach was adopted for analysis of the data which were generated by focus groups and in-depth interviews.

### **3.2 Stages in the Research Process**

The research process had five broad stages, set out below, together with discussion of the rationale and possible limitations of each.

#### **3.2.1 Stage One.**

Literature review of service user involvement in mental health in the UK.

This stage was largely completed early on in the research process, in order to inform the design and focus of the study and was updated throughout the research process. From this review it was apparent that the attitudes of professionals are crucial to the success of user involvement and that their expressed views and actual behaviour do not always match up. It was also clear that mental health professionals and service users often have different priorities. Finally, constraints to involvement would seem to cluster at the organisational level and some work has outlined how such constraints can be overcome.

### **3.2.2.Stage Two**

Analysis of the written questionnaire data generated by a survey of service users views regarding their individual care, which was undertaken by TNEY in July/August 2003.

The advantages of using these data are that they have already been collected at no cost in time or other resources to the researcher and are therefore an efficient source of data (Stewart & Kamins 1993). However the information is already likely to be outdated and the questionnaire was not designed specifically for this study and contains design faults, which affect its credibility. Edwards & Staniszewska (2000) argue that such surveys

“give little indication of a user’s experience of care, and what exactly it is that users are pleased with or would like improved. It is unlikely that such surveys are providing us with a reasonable reflection of users’ experiences of health care.” p418.

This limitation should not rule out the use of this material, but indicates that other methods should be used in conjunction with it. Unfortunately the author was only permitted to use the statistical data from this survey, as it was deemed by TNEY to be a violation of the Data Protection Act to permit the use of the ‘any other comments’ data. This would have provided some rich data in relation to patients’ feelings about care co-ordination, but access to these verbatim data were withheld on the grounds that the data were not collected specifically for the purposes of this study.

### **3.2.3 Stage Three:**

In-depth semi-structured interviews with key managers, professionals and service user representatives.

The following individuals were interviewed;

Service Manager for Mental Health, Redcar & Cleveland Social Services .

Locality Manager for Mental Health, TNEY NHS Trust

Service User Representative on the LIT

Service User Development Worker, employed by Mental Health Matters and managed by a sub-group of the LIT.

Consent was obtained and the interviews were taped and transcribed. These interviews allowed key individuals to discuss the meanings they attach to user involvement and how it can be developed. They also generated topics which were to be discussed in the focus groups. A semi-structured approach helped to ensure that the interviews were not subject to a rigid researcher-led agenda, which might have precluded the airing of some valuable insights.

#### **3.2.4 Stage Four.**

Focus groups of 6-8 people were held to explore user involvement. The groups lasted 45-60 minutes and were moderated by the researcher.

The following groups were held;

Service user group 'Greenlights' which is involved in the planning of services

Service user group from MIND, which is involved in the running of drop-in day services

A multi-disciplinary team of mental health professionals from the statutory agencies involved in the delivery of Care Co-ordination

A multi-agency group of workers from voluntary sector organisations involved in the delivery and planning of services.

Group discussions were recorded and transcribed. In the case of service user groups, another mental health professional with whom they were familiar was used to assist in moderating. However, the possible inhibiting effects of this are noted.

Whereas focus groups are usually comprised of individuals who share similar backgrounds but do not know each other (Morgan 1998), in this case pre-existing groups were used. This method was chosen because:

1. The groups already existed and were simple to recruit;
2. The vulnerable nature of the service user groups indicated that it might have been too stressful for many users to discuss sensitive issues with a group of strangers.

Participants were self-selecting in that the professionals were sent a written invitation to participate from the author, and the service users were firstly asked

as a group if they would like to participate, and then recruited by a worker from their host organisation to a maximum of 8 participants.

The focus group was chosen as the primary method of obtaining service users' views as it is an efficient way of generating large amounts of data (Morgan 1998) about the range of user experiences. However a great deal of preparation was required and the transcription and analysis were time consuming.

Krueger's (1998) work was used to inform the development of clear, brief and reasonable questions for the groups. Morgan (1998) states that focus groups are particularly helpful when there is a 'gap between people' (p57) e.g. service users and providers, as they illustrate possible different priorities and perceptions.

### **3.2.5 Stage Five.**

Data Analysis. Secondary data was evaluated according to 'recency and credibility' (Stewart & Kamins 1993 p17) with response rates and potential bias as influencing factors.

Qualitative data analysis was based on the transcripts of the interviews and focus groups. This enhances the objectivity of this crucial stage of analysis, by reducing reliance on the moderator's recall of each event.

The data are displayed by mapping onto a 'matrix of involvement' which illustrates the extent and variety of user involvement. The work of Dey (1993) was drawn upon to develop this tool.

In formulating conclusions the work of Miles and Huberman (1994) was used as a guide.

"From the start of data collection the qualitative analyst is beginning to decide what things mean – is noting regularities, patterns, explanations, possible configurations, causal flows, and propositions. The competent researcher holds these conclusions lightly, maintaining openness and scepticism, but the conclusions are still there, inchoate and vague at first, then increasingly explicit and grounded. (Miles and Huberman op cit.) p11

The diagram overleaf (Fig. 3.1) illustrates the research path undertaken with timescales.

**Fig. 3.1 Timetable**

	<i>February</i>	<i>March</i>	<i>April</i>	<i>May</i>	<i>June</i>	<i>July</i>	<i>August</i>
<b>Stage 1</b>							
Literature review update							
<b>Stage 2</b>							
Survey analysis & write up							
<b>Stage 3</b>							
Identify interviewees							
Obtain permission							
Develop areas to discuss							
Undertake interviews							
Transcribe interviews							
Analysis and writing up							
<b>Stage 4</b>							
Identify groups							
Obtain agreement							
Develop group questions							
Organise/book/invite							
Hold groups							
Transcribe groups							
Analysis and writing up							
<b>Stage 5</b>							
Write up findings and develop recommendations							
Binding of report and feedback to LIT and participants							

### **3.3 Resources**

#### **3.3.1 Human**

The research was undertaken entirely by the author and required an average of 30-40 hours of work per month during the project.

#### **3.3.2 Physical**

A digital minidisk recorder was used to record the interviews and focus groups. IT and printing facilities were available at the researcher's place of work and permission was obtained for this.

The focus groups were held at the service user groups' existing meeting places. The professional groups were held at a local hotel.

#### **3.3.3 Financial**

A budget of £300 - £500 was allocated for the purposes of this research. The two principal uses of this grant were for paying expenses to the service user participants at a rate of £10 each and to provide refreshments and a venue for the professional focus groups.

### **3.4 Ethical Considerations**

The researcher is aware that mental health service users constitute a vulnerable group and accordingly particular care was taken in the choice of research methods, as indicated earlier. The project is founded upon the principle of beneficence, in that not only was it be ensured that no harm was done to any participant, but that it is the participants who will ultimately benefit from the results.

To this end, a statement of informed consent, as set out by Morgan (1998) was obtained from participants (see Appendix 1) and they were assured of confidentiality to protect them from criminal/civil liability or actions affecting their finances, employability or reputation.

Confidentiality was ensured by:

1. Only the researcher and one other professional known to the users having access to recruitment information in the case of service users and in the

case of professionals only the researcher having access to recruitment information;

2. The discussions only used first names;
3. The minidisk recordings of the groups and interviews will be transferred into computer-readable form to be stored on a secure computer system for future reference/verification. The original disk recordings will then be erased;
4. Identifying information will be removed or modified.

The researcher explained to participants what the findings will be used for, assuring them that their participation was voluntary at all stages and that they could opt out or take a break. Participants were reminded that they all know each other and would continue to do so after the group and some boundaries on self-disclosure were agreed. It should be stressed that the researcher is a trained and experienced mental health professional who was able to detect signs of distress or potential over-disclosure in participants should they have occurred and could have taken avoiding action.

A commitment has been made to accuracy in this piece of research i.e. there are no 'fabrications, fraudulent materials, omissions and contrivances' (Denzin & Lincoln 1998 p 190).

In line with the ethical stance adopted, key findings will be fed back to service users and providers in briefing sessions to be held from September 2004 onwards.

### **3.5 Competence**

As a postgraduate student with a higher degree, I have some experience of original research, but am acutely aware that this project involved methods with which I was not very familiar e.g. the facilitation of focus groups. I prepared for this by studying, being supervised and advised on these matters, in order to ensure a good quality study.

## CHAPTER 4. FINDINGS AND ANALYSIS.

This chapter will be concerned with the results of the research and will use the concepts of public engagement theory to explore patterns and map the extent of user involvement in Redcar and Cleveland.

### 4.1 What Makes User Involvement 'Meaningful'?

As indicated in Chapter One, user involvement is a performance indicator for public service organisations such as the NHS and local authorities. Much of the discussion by participants in the study reflected a recognition that that such a requirement could lead to a 'tick box' approach to user involvement at the expense of quality and meaning in the experience. Respondents were asked what in their view made involvement meaningful for service users.

“(meaningful is) to move beyond tokenism, although tokenism is a good start if there’s no involvement at all...” (Service User).

A senior manager acknowledged that meaning is a subjective matter

“Meaningful involvement is when the service users themselves [...] think they are not just there as decoration or a token gestures. It’s how they feel at the end of the involvement as to whether it’s been meaningful. I can think of examples when we feel there’s been what we might consider to be meaningful involvement, but it perhaps isn’t for the service users...meaningful isn’t just about the extent of the involvement.”

Analysis of the responses suggests that meaningful involvement is related to two related clusters of experience; being valued and a feeling of relevance and ownership. Being valued, by being listened to with respect, was cited by most respondents, both service users and professionals.

“It’s important for services users not just to be there, but to be listened to and have the opportunity to contribute to agendas and to be able to understand what’s going on, rather than just sitting there, saying nothing because they don’t understand what’s happening anyway. So it’s important to create the right environment for people really to be able to understand and equal weight being given to their views as to the views of the professionals involved.” (Service User)

The notion of an 'equal footing' with professionals was supported by this senior manager

“It’s about people having felt believed, perceived that they’ve had a say...that that’s been an equal consideration, not more , but an equal consideration...and they can see that that has clearly been taken into

account in the decision and that a response to that involvement has been given.”(Senior Manager)

Receiving a response to involvement was seen as crucial to a meaningful experience by the service users. This response might take the form of either a change in services, or a reasonable explanation as to why a request could not be met.

One instance, cited by both service users and professionals alike, shows that responses do not need to be related to major decisions to be meaningful. The Greenlights group visited Teesbay ward, an acute in-patient unit used by the locality and were asked to give feedback on their findings. One of the issues was a general unhappiness with coffee being unavailable after 12 noon, as it was thought by staff to interfere with patient’s sleep patterns. Following the service user feedback, decaffeinated coffee was made available in the afternoons.

Service users commented

“We were asked to do a survey on the Teesbay ward [...] things got changed – that was a good thing, good feedback.”

“I think that’s really important. Previous to that I couldn’t get my head round the whole idea of service user involvement [...] but when that happened with Teesbay and a few other things happened, the police training... it’s started to make sense now for me and I’m getting to know what can be used.”

It was acknowledged that not all service user requests could be met, even within a user-led service. As a member of the MIND user group said

“The service users are asked ‘what would you like to do within the next three months?’ and we are listened to and if it’s possible money-wise or teacher-wise then they get it for us.”

A beneficial side-effect of user involvement was found to be an increase in the confidence of the service users. Whilst Barnes and Bowl (2001) advise against using involvement as a clinical intervention, as indicated in the literature review, it was nonetheless clear from both user focus groups that it is a common outcome from involvement. As one user put it,

“These things make me feel good about myself and I’ve had a forty year illness, feeling that I’m a second class citizen and struggling to keep my self confidence going.” (Service User)

The second, related aspect of meaningful involvement was a sense of relevance and ownership in the sphere of involvement. As one member of the MDT vividly illustrated,

“It’s got to be pertinent. In the past we used to set up community meetings to try and involve service users and hardly any came along and there wasn’t really any main agenda issues and for that reason people didn’t come along unless they were almost dragged in. So we thought ‘why are we doing this? Are we doing it just so we can tick a box to say we’re doing it?’ and it didn’t mean anything[...]then rumours got around about Boulby Suite closing and suddenly everyone came to the meeting because it meant something to them. Now they’re organising themselves as well - it’s nothing to do with staff, so because it’s something that’s important to people and means a lot to them, attendances are really good.”

Members of MIND, which is a largely user-led organisation, also supported this idea of ownership and relevance,

“It’s like we’re on the Exec. So we’re their managers, we employ them and we’re running MIND as a business, but we’re still service users.”

But when asked if they would want to be paid for this work they were unanimous that they did not.

“I’m putting something back into the organisation.” (Service User)

Another added

“a lot of people feel like that – it’s like a thank you. It’s been there for us”

At an individual level, senior managers pointed out that all service users should ideally be meaningfully involved through their own care.

“Meaningful for an individual is being properly involved in the decisions on their life which are made through a care plan.”

A service user of long-standing appreciated changing practices

“It’s a lot better. Twenty eight years ago when I first got ill things were completely different and the doctor just used to tell you what to do and there was no feedback. Then a new doctor started and changed the place completely.”

Clearly there are degrees of involvement, as outlined by Arnstein (1969), who developed a ‘ladder of participation’ reproduced below.

**Fig 4.1 Ladder of Participation**

DEGREE OF CITIZEN POWER	Citizen Control
	Delegated Power
	Partnership
DEGREE OF TOKENISM	Placation
	Consultation
NON-PARTICIPATION (TOKENISM)	Informing
	Therapy
	Manipulation

The responses from both users and professionals would suggest that enhanced meaning in user involvement is related to level of participation, but that this is not the sole variable in determining meaningfulness, as the level of participation is mediated through the way in which involvement is practised i.e. being valued and respected and the relevance to the life of the service user. Responses also indicate that for many users and in particular professionals, the desired outcome is partnership with users and not user control.

#### **4.2 The Extent of User Involvement in Mental Health Services**

The analysis of user involvement in services will examine the extent of involvement in three spheres of potential influence;

- i) Involvement in user's own care plan
- ii) Involvement in the delivery of services
- iii) Involvement in the planning of services.

##### **4.2.1 Involvement in Own Care Planning**

A variety of data have been used in the compilation of this section of findings. Firstly the user audit undertaken by TNEY in August 2003, which takes the form of a tick box reply to a variety of questions about service users understanding of and involvement in their own care. The audit process was considerably flawed in design, as will be discussed later, but is still worth including as it is the only

quantitative data available on this subject. The results of the interviews and focus groups will also inform the discussion to add a qualitative approach.

The Care Co-ordination process (also known as CPA) is the partnership approach to assessment and care management in mental health, developed nationally between Health and Social Care. Each locality is required to develop a Care Co-ordination Policy based on national guidelines. In the Standards and Criteria document produced in partnership between TNEY Trust and the six local authority areas it covers, Standard 5 states

“Service Users and Carers are actively involved in their own assessment and planning and consulted in service planning.”

Professionals are expected to be familiar with the policy and practice and the ethos of working together with service users in the process. This is borne out in some of the responses from professionals participating in the research.

“I would hope that there’s user and carer involvement in the actual delivery of their care...so whether or not they take medication for example, what type of medication, what suits them best.” (MDT member)

“I’d like to think that they’re involved in their own care plans and treatment through CPA reviews” (senior manager)

Generally the feeling amongst professionals was that service users were involved in their own care planning even if they were not interested in any wider involvement.

Many of the service users from MIND were not subject to CPA i.e. they were receiving mental health services from their GP (Primary Care) rather than from the specialist services (Secondary Care). However those service users who were subject to CPA were generally positive about their involvement as this extract shows;

Service User “I have a CPA which my social worker and my sister attends which is about what’s happened during that time and what problems and what we can do about them.”

Interviewer “And do you feel involved in that ?”

Service User “Definitely”

Several users pointed out that the crucial issue in care planning involvement is the attitude of the worker they see.

“You have an input, it’s up to the psychiatrist how much input you’re allowed to have about your medication. I was asked if I was happy to go on medication, rather than just being put on it. Having looked at the pros and cons, then I agreed.” (Service User)

There was also a feeling amongst groups that attitudes were definitely changing for the better

“There used to be a doctor and he’d just tell you ‘do as you’re told – you do what I tell you’. I didn’t like him. The new psychiatrists, the young ones are alright now. They’ve got a different attitude to the old school, it was a bad attitude.” (Service User)

Another added

“I went on a course with (organisation X) for manic depressives...a psychology course for six weeks on how to cope with my illness and learned to cope quite well and it’s done me a lot of good.”

Whilst it is not possible to generalise widely from the few user participants who were subject to CPA, it should be noted that all responses were generally positive. Those users who only see their GP had less favourable comments, for example

“Doctors are not giving people the chance to discuss their problems, they’re just saying, ‘here you are, here’s some pills’.” (Service user )

There was however a general agreement that younger GPs do listen more and prescribe less.

A wider user audience was reached by the audit of the Care Co-ordination process undertaken by TNEY NHS Trust with results broken down by locality. For Redcar and Cleveland 641 questionnaires should have been sent out i.e. one to each service user, but because they were distributed by the care co-ordinators, no record was kept of how many were actually sent. 116 replies were received, roughly 18% if all users received a questionnaire. The full results are reproduced in Table 4.1 overleaf.

**Table 4.1 Results of Service User Questionnaire**

	% Yes	% No	% not applicable	% DK
I have been told how information about me will be shared with other people	41	38	2	10
I have been given information about my illness	70	25	1	3
I know who my care co-ordinator is	70	20	1	8
I know who to contact when my care co-ordinator is not available	65	29	1	9
My needs assessment included assessment in the following areas:				
Accommodation	24	29	23	7
Income/benefits	34	28	14	5
Leisure/social activities	42	22	14	4
Daytime occupation (e.g. education, employment, voluntary work, day centre attendance)	34	28	17	5
Ethnicity issues	4	37	26	8
Disability issues	30	28	18	7
Gender issues	12	34	23	8
I have a care plan which is a written statement of my needs, how they will be met and who will be helping me. It includes (if applicable)				
Accommodation issues	16	29	26	10
Financial issues	24	28	20	10
Leisure/social issues	31	26	17	9
Daytime occupation	14	30	23	11
Ethnicity issues	4	36	27	9
Disability issues	20	32	22	10
Gender issues	11	34	27	11
I know how I can make sure that differences of opinion between me and the care team are recorded	37	34	6	20
I have agreed my care plan	61	15	11	13
When I left hospital I was visited by a member of the care team within 7 days	13	6	12	1
The care team always				
Listen to me	71	2	10	4
Treat me with respect	71	3	8	3
Respect my privacy	70	2	8	4
Maintain my confidentiality	64	1	8	11
I have a full review of my care at least once per year	53	16	7	16
At the review I was given the opportunity to say				
How I felt	66	11	10	6
Whether I felt the services were supporting me	53	14	11	7
What, if anything, should be changed	47	17	11	9
Whether anything in my life has changed	41	17	11	7
I was offered an advocate to				
Help me prepare for the review	20	41	20	7
Support me at the review	24	36	17	6
Speak for me at the review	23	37	17	8
There is a risk and relapse management plan which				
Has been discussed with me and I understand how and when it will be used	24	42	7	20
The risk and relapse management plan states				
What has helped me on previous occasions	30	25	12	23
A contact number and out of hours contact number	40	25	13	15
What will be done if my carer cannot support me any longer	21	30	20	22
My carers and I have a number to use where we can contact someone 24 hrs per day	54	28	3	10
I have been told how to make a complaint	37	47	3	5
I was given some choice as to who would be my care co-ordinator	20	55	10	10
My choice in relation to my care co-ordinator included in particular				
Ethnicity	6	33	23	15
Gender	10	33	24	13
Discipline (e.g. CPN, OT, Dr. etc)	19	33	22	15
When I moved from one service to another, or from hospital to residential care, staff from both settings met with me to review my care plan	31	26	31	5

As well as uncertainty over the sample size, the survey was flawed in other ways;

- i) It assumes respondents are literate
- ii) It assumes that they understand that the MDT member who they see is acting as 'Care Co-ordinator' in relation to them
- iii) It assumes familiarity with words such as ethnicity, gender etc. and generally uses management terms to ask questions about service users lives
- iv) There were no explanations of the questions
- v) No questions were included about satisfaction
- vi) Some co-ordinators offered help with filling in the form and delivered the form by hand, whilst others simply posted them

Consequently it is not possible to be sure what all the answers mean. However, some tentative comments are offered concerning the less ambiguous questions. Whilst the majority of users had been given information about their care plan (70%) and had agreed their care plan (61%), responses suggest that Risk/Relapse Management Plans are only being developed with the involvement of a minority of service users (24%). Also only 20% of users were given a choice of care co-ordinator and as a locality Redcar and Cleveland is still poor on offering advocacy (24%), which suggests that user involvement in care co-ordination is still underdeveloped, to a degree not appreciated by professionals. The Commission for Health Improvement (2003) reported that nationally

“there is a gulf between user and Trust perceptions of user involvement in care planning. Service users commonly report that they are not involved in their own care planning, do not have care plans and do not have their care plans reviewed, whereas Trusts report that users are involved. This difference...reflects the reality that mechanisms for involving service users in their own care are ineffective.”

However the majority of service users felt as though they were listened to (71%) and respected (71%) which as discussed earlier in the chapter, is likely to render the experiences more 'meaningful'. It is difficult to extrapolate further from this data, owing to the marked flaws in the survey design and implementation.

## 4.2.2 Involvement in the Delivery of Services

The following sources will be used to review the extent of user involvement in the delivery of services;

i) Interview and focus group findings

ii )A review of Patient, Carer and Public Involvement April 2002–Sept 2003 undertaken by TNEY

Involvement will be examined according to the 3 stages in the participation continuum outlined previously i.e. receiving information, being consulted and being an agent in control.

### 4.2.2.1 Receiving Information about the Delivery of Services

It is apparent from the discussions held with the MDT group that professional care co-ordinators see part of their role as giving information about care options, as this extract illustrates;

Interviewer “Do you see yourselves as care co-ordinators having a role in service user involvement ?”

Professional 1 “I think so because we’re working with them every day, we’re looking at them making choices about their life every day”

Professional 2 “And, let’s be honest, in some cases trying to influence those choices.”

Professional 3 “That’s our job, to give them the correct information so they can make the right choice.”

Despite the acknowledgements by the professionals that information sharing is crucial to their role, a note of concern is evident in the words of this senior manager;

“We don’t give people enough information about options in care planning – we’re still very much resource-driven. So we still use our pick list of Community Support, Day Services, Employment Services....Other than... saying ‘let’s turn this round and ask what do **you** want to do?’”

This information-giving role is also undertaken by the Day Services and the service user involvement groups. Greenlights members felt that information exchange was an important part of the group’s function

“We’ve had guest speakers as well and we’ve been able to ask questions that probably otherwise we wouldn’t have been able to ask. Like asking questions to psychiatrists and finding out information that we need to know as service users and equally giving them our point of view from where we’re coming from.” (Service User)

#### **4.2.2.2 Consultation About the Delivery of Services**

There is ample evidence that indicates that there is a great deal of consultation with users about service delivery in the Locality. Annual surveys are undertaken by both TNEY and Social Services, as well as annual user input into the Autumn Review process required by the DOH to gauge progress in implementation of the NSF. The voluntary sector service providers also consult with their service users regularly on a more informal basis.

Increasingly service users are represented on various local and Trust-wide committees which oversee service delivery. E.g. The South Tees Acute In-Patient Care Forum and the Trust-wide Mental Health Act Steering Committee. Service Users are also being involved in the training of professionals, both within and outside Mental Health Services e.g. Approved Social Worker training (for social workers who will subsequently be authorised to detain patients under the Mental Health Act 1983) and police training; a development which has grown from Greenlights inviting the Redcar Police Mental Health Liaison Officer to one of their meetings.

“We heard that there’s probably an hour of mental health training within the (police probationary) training and the police liaison officer said...we’re not told of what illnesses are which...so we’ve got a board of about ten service users who are willing to get involved and they’re each taking on...(an illness) where they talk about the illness and how it can manifest itself and things to watch out for when the police are in their role.” (Service User Development Worker)

#### **4.2.2.3 Service Users Exercising Control in Service Delivery**

It is within the delivery of mental health services that Redcar and Cleveland's services users exercise the most control. Day service provision in the locality is contracted out by Social Services to MIND and Mental Health Matters and built into the contract specification was that service users had to be involved in developing the programmes that take place. Particularly in the case of MIND, where nearly 90% of the current Executive Committee are service users, this represents genuine control of service delivery by users. As the (non-service user) Director of Redcar MIND summed it up

“They (the Exec.) participate in recruitment and selection, a newsletter, if we’re writing our Business Plan everyone takes part in it...everything to do with service delivery and planning goes through the Exec. ...policy, planning, decision-making...it’s just an ongoing thing.”

Mental Health Matters also has a local user-produced and managed newsletter and Creative Support are starting one up. TNEY has developed a Service User and Carer Leadership Programme which has been much praised by participants

“I’m almost proud to be a service user; it was tremendous” (Service User)

The same individual is now on the National Board of Trustees for Mental Health Matters. TNEY are also hoping to employ an STR worker (Support Time Recovery worker) on the in-patient unit who has experience of mental health problems.

STAMP Revisited is a user led and run organisation, which “exists to provide independent, free and confidential advocacy to people with mental health issues, supporting and empowering them to put forward their own views.” ([www.stamprevisited.com](http://www.stamprevisited.com) accessed on 27/07/2004). Advocates are often service users or ex-services users and they offer services to individuals, such as attending CPA meetings with them, as well as to groups such as in-patients, who may wish to complain about something for example. The service is available across both the Redcar and Cleveland and Middlesbrough Localities and is based at St. Luke’s Hospital.

#### **4.2.3 Involvement in the Planning and Development of Services.**

This section utilizes the same data sources as the previous one and is also examined according to level of participation.

##### **4.2.3.1 Receiving Information about the Planning of Services**

All statutory organisations are obliged to provide some sort of public information regarding future service plans. Redcar and Cleveland Social Services issue the Service Delivery Plan which is available to the public, but not directly distributed to services users. TNEY have a long term Business Plan known as ADVANCE and has held a series of stakeholder days which have included services users, to inform and consult regarding the proposed plans.

#### **4.2.3.2 User Consultation in the Planning and Development of Services.**

As with the delivery of services, user involvement activity in the locality appears to cluster around consultation in relation to service planning. Several service provider organisations involve users in recruitment and selection procedures as this Greenlights member explains

“When there’s jobs going I usually sit in with the interviewers and I’ll be asking some of the questions as well and I’ll be involved in marking and assessing that person and my opinions are recognised”  
(Service User)

And another states

“There’s been opportunities for service users to be involved in the TNEY Trust’s recruitment processes...undertake training and I’ve been involved in a couple of rounds of recruitment now and it’s quite rewarding and interesting for the service users....that is something that shows it’s not just about meetings and discussions, it’s...penetrating the organisation from lower down and having influence at a different level.” (Service User)

MIND and Creative Support also involve users in recruitment, following a training programme to enable them to do so. Social Services would appear to be lagging behind in this respect, having a very low staff turnover and tending to rely on the fact that their contracted-out services involve their users in recruitment. Recruitment and selection will be explored in more detail later in this chapter as participants indicated that the process of involving users is not without its problems.

Service users are represented on the LIT which oversees the implementation of the NSF for Mental Health in the Locality. There are currently two user seats on the committee which are filled on a rotational basis by three users. The group meets monthly and includes representatives from all statutory and voluntary mental health agencies as well as users and carers. The experience of individual users involved in this group will be explored in more depth later in this chapter as in many ways its history mirrors the development of user involvement generally in the Locality.

As indicated earlier, the Day Service providers consult their users regularly about the types of activities on offer and in MIND are involved in developing the Business Plan. Creative Support, who run a rehabilitation hostel in Redcar,

regularly involve their residents in everything from proposed activities to weekly menus and interior décor.

An area which is increasingly attractive to user groups locally is mental health promotion and awareness raising, as they seek to challenge the stigma of mental illness. World Mental Health Day in October 2003 was marked by a range of activities, some in Redcar High Street, involving users, the voluntary and statutory sectors, “taking the mental health issue to people” as one service user described it.

“It does help when MIND has these weeks (Mental Health Week)...it helps to make the public aware, so that’s really the reason why MIND is run – to make the rest of the public aware that there is somewhere for someone to go who has got mental health problems.” (Service User)

Recently Redcar and Cleveland’s service users were involved in the launch of the Teeswide Suicide Prevention Strategy with an audience of the areas MPs. Chief Executives etc.

#### **4.2.3.3 Service Users Exercising Control in the Planning of Services**

It was not possible to identify any activity in this area, and the work of Peck et al. (2002) suggests that in order to do so, it would be necessary to have a user-run LIT, which would fly in the face of the Government’s policy on partnership working in Mental Health Services and is consequently not necessarily desirable. Participants shared a broad agreement that it would be desirable to extend the range of users who are involved, but no participants advocated users controlling the LIT. A user chairing the LIT would not be out of the question however.

#### **4.2.4. A Matrix to Demonstrate the Extent of User Involvement in Services.**

In order to make the extent of user involvement in the locality more readily understandable, the various activities outlined above have been plotted on the following matrix, (see Fig.4.2) adapted from the work of Peck et al. (2002). The matrix utilises the three levels of involvement outlined earlier in this chapter; user as recipient of information, user as subject of consultation and user as person in control of their care. It also maps these against the three areas of involvement, which are the subject of this study; Care co-ordination, service delivery and

service planning. Some items are located in the box which is the best ‘fit’ but will also be appropriate for other boxes and are not necessarily exclusive to one.

**Figure 4. 2 Involvement Matrix: Redcar and Cleveland**

<b>Area of Involvement</b>	<b>Receives Information</b>	<b>Consulted</b>	<b>Agent in Control</b>
<b>Care co-ordination</b>	Receives care plan Receives information about illness/ treatment	Agrees care plan Negotiates medication	Choice of co-ordinator
<b>Delivery of Services</b>	Receives information about Services (via co-ordinator, Greenlights, Day Services)	User surveys Autumn Review Reps. On operational committees Training of professionals	User-run services User-run newsletters STR workers STAMP
<b>Planning of Services</b>	Receives information about Service Plans e.g. Service Delivery Plan, ADVANCE	Reps. on LIT Recruitment and Selection Involvement Day service planning	

It can be seen more vividly from this matrix how local user involvement activity clusters around the consultation level and the service delivery area, with information-giving less developed and little in the user control column with the exception of the running of Day Services. However, it also illustrates the increasing volume and diversity of user involvement in the locality and the potential for service users to move between levels.

This section represents a snapshot of user involvement; the next two look at the issues behind the picture – participants views on factors inhibiting user involvement and their suggestions as to how these might be tackled.

### **4.3 Factors Inhibiting Service User Involvement**

The data used in this section will be the responses of the professionals and service users who participated in the primary research. Respondents were all asked the question “*What do you think are the barriers to service users becoming more involved in services?*” The resulting barriers mentioned will be examined at three levels; individual, organisational and societal, as the responses and the

literature (Hickey and Kipping 1998) indicate that barriers operate at all these levels and interact in a complex manner. Fig. 4.3 below gives an overview of the different levels and contexts where such barriers were found in Redcar and Cleveland. The following sections detail these.

**Fig. 4.3 Barriers to Involvement**

	<b>Individual</b>	<b>Organisational</b>	<b>Societal</b>
<b>Structural</b>		Nature of meetings Representation Management of service user development post Benefits system	
<b>Cultural</b>	Experience of mental illness Attitudes towards the mental health services	Professional attitudes Service user attitudes	Stigma surrounding mental illness

### **4.3.1 Individual Inhibiting Factors**

Whilst some service users will not be involved in services simply because they are unaware that they can be (a publicity issue) it is highly unlikely that the majority of them would become involved easily even if they were aware of the opportunities. This is due to the nature of their experience of mental illness and receiving treatment for it. Various individual inhibiting factors were cited by respondents which related to both the individual's experience of their illness and their individual attitude to the mental health services. These two categories are explored further below.

#### **4.3.1.1. Individual Experience of Mental Illness.**

As with some physical illnesses the experience of stress can accelerate onset of a mental health problem, or induce relapse in those with a predisposition or 'vulnerability' to mental illness (Zubin, J. and Spring, B. 1977). Not only this, but mental illness tends to sap both an individual's confidence and motivation, both of which are likely to affect inclination to become involved.

“If people are ill, then they don’t even want to go out and it’s an effort to do anything and they’re not going to go to meetings” (Service User)

“It’s the mental health problem itself – having a mental health problem is going to stop you from doing those things (getting involved) – your confidence isn’t going to be so good, you’re not going to feel you can voice things as you normally would.” (MDT member)

For other service users who are detained under the Mental Health Act, it is likely that they feel disempowered

“When you’re an in-patient you’re generally in a parlous position, because a lot of people are there against their will. So I feel that as an in-patient they would feel it inappropriate (to get involved) because of their circumstances.” (MDT member)

Even in those who are recovering and keen to be involved at some level, the effect of involvement needs to be borne in mind.

“You can offer that (a place on the Acute Care forum) to somebody who you think is quite passionate about having been in hospital and wanting to change things for the better, however for them to go and sit in a meeting where they’re talking about these things, may not be good for their progression in their mental health.” (Service User Development Worker)

“Constantly trawling over the issues, focussing on the fact that you’re mentally ill – you’re reminded because you’re going to the meeting and talking about it – you have to watch for the effect on people’s psychological well-being.” (Service User)

#### **4.3.1.2 Individual Attitudes towards the Mental Health Services.**

An individual service user’s relationship with the mental health services is often ambiguous, given the nature of the problems outlined above and society’s attitude to mental illness, which will be explored later in this section. Not surprisingly, some service users just want to put the whole experience behind them.

When one care co-ordinator tried to get service users to take up an issue that they felt strongly about, he found

“One individual said ‘no, I’ve been in, I’m out now, I just want to put it behind me and just move on’ and the other said ‘It’s not my place to be doing things like that’” (MDT member)

Others are fearful that they will be identified as troublemakers and this will adversely affect their care.

“There is some element of fear that if you get involved...that it might affect your own care and treatment in some way...I’m not saying it has happened, but there is a feeling that you don’t want to be known as a troublemaker or it might reflect on you in some way.” (Service User).

“I think it’s about not knowing the right channels to use and not feeling comfortable about using them. They might be deemed a troublemaker or the staff might not be as nice[...]next time I go in there. I think there’s a genuine fear.” (Comment from MDT member which generated general agreement in the group).

A lack of trust about why involvement is being encouraged was evident in some of the responses

“It was mentioned by a lady the other day where she said ‘I really want to get involved with the police things, but I just hope that we’re not being laughed at when the door is shut’ [...] it is a concern for people that they are being taken seriously, that it’s something they’re going to be welcomed into, not taken advantage of.” (Service User Development Worker)

“There’s [...] still sometimes the suspicion on the part of service users as to why they’re being asked to be involved – I suppose that’s about the power relationship between the professionals and the service users.” (Senior Manager)

Finally, getting involved may not be high on an individual’s list of priorities for a host of other reasons

“I think the barriers for some people being involved is that...they have lives out there and jobs and kids and houses and hobbies; some people don’t want to be involved and that’s perfectly OK, but if you look at it the way I do, then they are involved, because they’re involved in their own care.” (Senior Manager).

### **4.3.2 Organisational Barriers to Involvement**

A senior manager in the Locality estimated that there are approximately 1500 citizens of Redcar and Cleveland who are under the care of the secondary mental health services and yet out of those.

“You might only get the views of a handful”

The previous section examined the individual reasons which many of these service users have for not becoming involved more; this section explores the

organisational barriers which inhibit wider involvement. From the research, two broad categories of organisational constraints emerged; structural and cultural, each of which will be examined in turn.

#### **4.3.2.1 Structural Organisational Barriers to Involvement**

The structural barriers to involvement are those concerning the way business is conducted in the Mental Health Services and are probably the most obvious to an observer.

##### **4.3.2.1.1. The Nature of Mental Health Service Meetings**

Partnership working, whilst invaluable in terms of providing a seamless service, often involves meetings of large numbers of people, which for reasons of scale can tend to be more formal in nature than a small group. For example if all the members of the Redcar and Cleveland LIT attended the meeting, there would be at least twenty people around the table. This can be very intimidating for service users, although there is evidence that in terms of the LIT meeting this is changing, as one long-standing service user member of the LIT explained

“The LIT meeting is really good and it’s greatly improved...it’s generally quite informal, but it works well because of that now. It was very intimidating when it was more formal and constantly worrying about when it’s your place to speak...there seems to be a genuine exchange of views because you’re not so bound up in the protocol of it. I’ve now got to the stage where I will just ask questions...but I know (the other service users) were too intimidated to ask and so they totally lost the thread of the discussion...I think there could be more opportunity for briefing and de-briefing.” (Service User)

Professionals are evidently aware of this difficulty

“Sitting on the LIT for service users is really confusing...a lot of it isn’t relevant...and it’s very difficult for someone to engage or even feel confident to give an idea at that table...it’s daunting.” (Voluntary Sector Manager)

However, even if the meetings are not all so formal, there are other difficulties which service users encounter,

“I tend to stay away from the LIT meetings and things like that...it is so much more a formal setting and you do need to be aware of jargon...I don’t like the fact that you need to become some sort of expert to be able to talk to them.” (Service User)

Professionals are aware of their use of jargon and often display a sophisticated understanding of the issues, but little seems to be done to counteract it.

“I think it’s down to communication as much as anything. Quite often it’s apparent to me how often we use jargon – we try not to, but we still do and that doesn’t help with shifting the power balance, because sometimes people haven’t a clue what you’re talking about and they need to be fairly confident to be able to say ‘what do you mean by that?’” (MDT member)

Sometimes a service user can have overcome these barriers, only to find that the professionals have received the agenda before the meeting, unlike themselves.

“I’ve felt really isolated before, in terms of getting the agenda just immediately before and thinking ‘what does that mean?’...but you haven’t a chance to ask, so you’re spending the first part of the discussion trying to grasp what it’s all on about...never mind being able to have a thought around it.” (Service User)

Often a service user can be deterred from involvement in a committee simply by the timing or the location of the meeting. Several major management meetings are held at ST. Luke’s Hospital (which houses the acute in-patient unit) largely because if it is a Trust-wide meeting of a joint forum with the Middlesbrough Locality, it provides a central location with no added costs. However for the service user it can mean the difference between attending and not attending.

“Certain things that people have wanted to get involved in, the location’s been wrong for people. For example if they don’t want to go back to the hospital setting where they were, for obvious reasons, so a meeting held there does put people off from becoming involved.” (Service User Development Worker)

Another practical barrier is the timing of meetings,

“Are we flexible enough around having meetings to enable service users to...attend? I mean I’ve never known any planning meetings to take place on a Sunday afternoon for example, but they may take place a 9 o’clock on a Friday morning when service users are perhaps otherwise engaged. So there isn’t a great deal of flexibility around when we have our meetings.” (Senior Manager)

Service users have also complained that meetings without breaks can stretch their concentration too far.

The evidence suggests that professionals are aware of most of these issues, but perhaps convenience is still dictating how meetings are held. Sometimes professionals who are committed to service user involvement feel unable to do more;

“There are those who haven’t felt comfortable in a CPA review situation and a co-ordinator you feel responsible in some way

because the person knows you better...you're limited in what you can do because everyone is required to have a CPA review...you try and think about all the ways in which you could make that setting more comfortable, but you might not be able to...and that can make me feel quite inadequate." (MDT member)

#### **4.3.2.1.2 Representation**

The literature indicates that questioning the representativeness of a service user, who attends a meeting, is a frequent criticism by professionals and as such represents an attitudinal barrier to involvement. However, representation is an issue in Redcar and Cleveland because the users who become involved tend to be those involved already in Day Service attendance.

"It's reaching all the service users - we do have representation, but if you're not careful it's the same people who turn up at the various meetings...they tend to be the ones who are readily accessible, for example sitting on wards or in day services. The people who sit at home and don't engage in the wider services are very difficult to [...] access" (Senior Manager)

To compound this, several MDT members commented that the Day Services, particularly in East Cleveland, only tend to attract older service users with younger ones being put off, so that

"If you don't like the service, you're not going to go [...] so you're not going to have your say." (MDT member)

It can be quite a strain for a service user representative to feel that they are fulfilling their role adequately, even given the above limitations;

"I think it's really hard for representatives to consult totally widely and be really democratic – just how can you do that? I initially started off trying to be really democratic and report back everything to everybody and get everyone's views on things, but...it's just not practical and you can't say 'what do service users think?' as they're not going to think one thing, because they're individuals and they're all going to think different things." (Service User member of the LIT)

Greenlights, the service user involvement group, have struggled to reach a broad base of service users

"We were aiming to have a borough-wide forum and go out to get as broad a membership as possible from all sectors, including primary care, or people who may not have been in contact with any services but did have mental health issues...but it's just been very, very, difficult – the membership is much smaller than I would have hoped for at this stage...I know that we have tried lots of different things...to

get a broader range of people involved, but it seems to be... mainly people from day services who seem to be involved.” (Service User)

#### **4.3.2.1.3 The Management of the Service User Development Worker Post.**

A structural issue which may be contributing to the above situation, despite the hard work undertaken by the able and well-respected individual employed as Service User Development Worker in the Locality, is the arrangements for the management of that post.

As indicated in the introduction, it was decided to employ a Development Worker with time-limited Neighbourhood Renewal Fund monies and that the management of the post would be by a multi-agency sub-group of the LIT. Line management of the individual in terms of payroll, sickness, holidays etc. was situated within Mental Health Matters, which is based at the Grange, where they also run one of the four Locality day time drop-in centres. Respondents indicate that the Development Worker post and by association Greenlights has been over-identified with that Day Service. Of the participants in the focus group at MIND, only one of them considered themselves to be a member of Greenlights and most respondents said they had 'no idea' what Greenlights did. Mental Health Matters as an organisation was identified by some respondents as being a restricting and controlling force in the activity of the Development Worker..

“It seems to have just been seen and accepted as the Mental Health Matters host and that’s one of the reasons we’ve had difficulty in attracting a broad range of members, because people think ‘oh, that’s the group from the Grange’ and (the development worker) is treated as a member of the Grange staff...their policy is in conflict with what the group’s trying to do and they’re generally trying to ...control a lot in her work. I understand there’s employment law and all the rest...but...that wasn’t spotted that...was a potential problem early enough.” (Service User)

The Development Worker also alluded to difficulties relating to Mental Health Matters policies, such as the need for risk assessments to be undertaken on all their service users. This has been extended to cover all attendees at the Greenlights group, which is not a MHM service, much to the dismay of members. As a consequence of not implementing risk assessments on Greenlights members, MHM have insisted that their meetings must not be held at other

venues in the Locality (for Health and Safety reasons). As the Development Worker stated

“We’re trying to be an independent body covering Redcar and Cleveland, whereas Mental Health Matters have their policies while we’re under them...so my development job has been about creating an independence for the Greenlights group...Mental Health Matters have listened and are trying to make sure they have separate policies to cater for us, but it’s about breaking the mould...it’s quite a restriction at the moment.”

During the first half of 2004 much debate concerned the future funding of the Service User Development post, as the NRF monies were due to expire in August 2004. There was a great deal of speculation and anger from service users and some professionals, that no further funding had been identified. Social Services earned a great deal of (unwarranted) criticism as many people believed that the post was funded by them in the first place, which was not the case. Service users felt that not to fund the post was an indication that their involvement was not valued. They indicated that ultimately they would like to run Greenlights themselves, but did not feel ready for this yet, although others thought that an exit strategy for the worker had not been given enough thought. However, during the course of the research further funding was made available to enable the post to continue on a part time basis with the worker being employed as a Senior Support Worker with MHM for the other half of her time.

The employment of a paid (non-user) worker is an issue for some service users

“Because we went in with a paid development worker, I think the self-sufficiency just hasn’t been there – there’s been an element of paternalism all the time, which I think some other groups in the Trust area are really adamant that they won’t have. They really do want to run every aspect of it themselves, but that does take a lot of commitment” (Service User)

#### **4.3.2.1.4. The Benefits System**

As outlined in the literature concerning incentives to involvement and accepted good practice, the payment of service users for their involvement is to be encouraged. However this intention is thwarted by the lack of flexibility in the Benefits System.

“We’ve struggled terribly in reimbursing service users for their time...the problem being the benefits system, in that the majority of

service users that we engage with are subject to sickness benefit...they have to be very careful they don't bar themselves from benefits because of their involvement with work...some areas do it, but we haven't managed to do it other than pay expenses locally...the advice you get from the benefits system is quite strict; there is a limit of £10, but then there's also potential conflict with the minimum working wage, so if you are paying people you're expected to pay them the minimum working wage." (Senior Manager)

"I know a lot of people, myself included, would have worries about benefits and the implications there." (Service User)

"You end up being too nervous sometimes...worried that if we put the cheques in our bank accounts that it would lead to problems for us." (Service User)

Responses indicate that payment for involvement is not a major incentive without which users would not become involved; more that it is a recognition of work completed. However, there does not appear to be a pathway for users to develop their involvement into something more like a paid job, without falling foul of the system.

#### **4.3.2.2. Cultural Organisational Barriers to Involvement.**

The cultural/attitudinal barriers to user involvement can be largely broken down into professional attitudes and service user attitudes. By far the greatest participant responses were clustered around the attitudes of professionals, which would tend to support the literature findings which indicate that professional resistance can be a crucial barrier to user empowerment.

##### **4.3.2.2.1 Professional Attitudes**

Service users tended to feel that professional attitudes were changing for the better.

"I can see changes and I can see that service user input is being actively sought out now, whereas before I felt like we were a bit of an irritation and it was very grudging 'because we have to' and I've seen some quite striking attitudes from some professionals, going from obvious impatience when I spoke at meetings or queried things to being very positive and encouraging now." (Service User)

However, there appears to be a lot of scope for improvement still in the eyes of most participants;

“I sometimes get the impression that if service user...representatives are there on contentious issues, those issues are dealt with outside of the meeting.” (Service User)

“I suppose there’s still reluctance amongst some professionals to meaningful involvement ...it’s almost as if the service user comes along and plays the game it’s OK, but if they come along and cause a nuisance, then professionals quite often avoid them.” (Senior Manager)

A useful illustration of the attitudinal ambiguity of some professionals is provided by the issue of service user involvement in recruitment and selection. Users have been used quite widely in the Locality as interview panel members, but confidentiality appears as an issue for some professionals because of the possibility that the interviewee might subsequently have a role in the user’s therapy.

“There may be certain questions that you would have wanted to ask the person being interviewed that you possibly wouldn’t have (if a service user was involved). If the person had...a past criminal record...you may have wanted to...(say) ‘I recognise this is a conviction from a long time ago, but can you tell me how that came about,’ where you possibly wouldn’t if there was a service user involved...we may look at the circumstances around that previous conviction, but still decide to employ and if that person then needed to be involved in the care of the person who’d been on the Panel, then the service user might have a biased view about them as a professional...I have to say that on the whole I still think it’s a good idea (to have service users involved).” (MDT member)

Another was less sure,

“There were some people ...I would not have been happy choosing...because they’re our own service users and maybe their illness is the sort that ...if they became high they might go saying things, because you have to have that trust...with everything, addresses and details about potential future staff.” (MDT member)

Members of the Voluntary Sector group had also dealt with these issues, but had resolved them by blanking out personal details from application forms given to all interview panel members, treating everyone equally, as this extract shows

Participant A: “We (MIND) treat them all the same and that’s a risk we take with a worker and a service user, but they all have our confidentiality policy...and they have to adhere to them.

Participant B: Also with the recruitment the service user might want to pick somebody because they’re better looking.

Participant C: So might the workers!”

On the whole the responses of all levels of professionals were very positive concerning user involvement, with a particular commitment evident from the top levels of management, particularly in the statutory sector. However, further research might be useful to look at any gaps between expressed views and observed practice at all levels.

#### **4.3.2.2.2 Service User Attitudes.**

As the diagram in the introduction illustrates, there is a web of organisations involved in mental health service provision. Service users frequently spoke about the fundamental difficulty of understanding how the organisations are interlinked and what role the individuals within them played.

“I don’t understand how it all fits together.” (Service User)

“It’s more about understanding the role that these people play within the service and understanding how you can have an input and how that can change things...not so much going to a meeting and feeling a bit intimidated, that’s always going to be a fact, but...it’s more the rest of it.” (Service User)

A Senior Manager recognised this as a problem,

“It’s lack of understanding of not just what we’re talking about, like LDPs and PCTs – we can rectify that...it’s that experience teaches us how a system works and it’s experience of working and operating within that system...I don’t think that’s something you can explain to someone.” (Senior Manager)

Of those service users who are getting involved in services and may have overcome that difficulty, there is the danger, as reported by some, of feeling overloaded by the increasing demands upon them. Greenlights have consequently turned down some offers to get involved;

“With so much service user involvement coming to us, we’re finding we can’t fulfil all of it because people can’t do too much.” (Service User Development Worker)

The nature of the Greenlights group itself is worthy of further exploration, as it is acknowledged to be a very ‘moderate’ group in approach, compared with some of the more militant ‘survivor’ groups which exist in other areas of the country. Opinions were divided as to whether or not this is desirable. When asked what could be done to address barriers to involvement, one senior manager expressed some frustration with the group,

“I’d like to think that something like the service user group would be raising the issues...it isn’t as vociferous as perhaps it could be. We have quite a non-threatening service user group...that could mean we provide excellent services and that nothing has to be changed, but I don’t see the militancy that you see in other places.” (Senior Manager)

The Service User Development Worker felt that this ‘moderation’ was in part deliberate

“We’re trying to be a positive group, not a negative group – we don’t want it to be us and them, we’re trying to work in partnership with the services.”

And partly a result of not needing to be militant because the attitudes of professionals in the locality are supportive

” They’re listening to what we’re trying to do and they want to be involved...I think if it was any other way my job would be extremely difficult.” (Service User Development Worker)

#### **4.3.3 Societal Barriers to Involvement**

A glance through the national newspapers will give the reader an idea of how much of British society views its mentally ill citizens. Allusions to ‘schizophrenic killers’ and the dubbing of former boxer Frank Bruno as ‘Bonkers Bruno’ are all too common. As this senior manager points out, as with many types of prejudice, the subjects of that prejudice often adopt society’s prevailing view about their own group’

“The stigma issue is always going to be there; but some of the stigma comes from the users themselves. I have service users in the community who say ‘I’d never go to St. Luke’s’, they’re all mad in there’. So it’s not like there’s this group of service users and the there’s these other people who stigmatise - it doesn’t work that way.” (Senior Manager)

One of the voluntary sector providers echoed this observation and how it acts as a barrier to involvement for some users;

“We have problems with stigma [...] a lot of the residents who were in the hostel and are maybe living in the community with outreach support, just really don’t want to be associated with mental health services and don’t want to be involved in a formal forum because they see part of their recovery as getting away from services.” (Voluntary Sector Manager)

Members of the MIND group agreed and gave examples of how people they know can’t understand why they would want to be associated with MIND.

“A man said to me, ‘Fancy having your picture in the paper associated with MIND, don’t it bother you?’” (Service User)

However, for this group of service users MIND represented a haven where they could ‘be themselves’.

“It’s normality – that’s all we’re wanting and it’s normality we get and we’re listened to and it’s not that ‘oh what do they know? ‘We do know what we’re about. I mean we interview people for jobs here and have a say the same as the paid workers.” (Service User)

With a complex set of individual, organisational and societal barriers, the responses illustrate that tackling the issue of developing service user involvement is not likely to be straightforward. The following section looks at the strategies which were suggested by participants in the study for breaking down the barriers they had identified.

#### **4.4 Participants' Suggestions for Overcoming Barriers to Involvement.**

It will be remembered from Chapter One that one of the research objectives is to consider ways of overcoming local constraints on involvement. To this end participants were asked for their suggestions as to remedial actions which would be useful locally. Some recommendations involved a change in attitude or actions on the part of professionals, whilst others were aimed at addressing practical barriers. Some respondents also set out their own vision for future user involvement.

##### **4.4.1 A Change in Professional Attitudes**

The role of the care co-ordinator was seen by many participants as crucial in encouraging user involvement,

“It needs to be more proactive and...I think the key people to a lot of this are the ...co-coordinators who work with the individuals who perhaps aren’t as encouraging as they should be to get people to get involved.” (Senior Manager)

“I think professionals could have a larger part to play in that if key workers...spoke to individuals about it – no pressure obviously because it’s not for everyone, but if it was raised by the people who have most contact with the service users..” (Service User)

This proactivity was viewed as information-giving about the range of involvement, and as encouragement to try it.

“If everybody had clear information about the opportunities, then they could make their own informed choice about whether they want to do anything. Quite often you come across people who are quite keen and they say ‘well why didn’t I know any of this?’” (Service User)

The Service User Development Worker felt that an enthusiastic staff member could be crucial in the success of a new development and that perhaps others needed more education about user involvement. It was regarded by one senior manager to be incumbent on staff to challenge resistant attitudes to user involvement,

“It’s a bit like the racism thing isn’t it? If you’re going to hear and see that attitude but not individually take the responsibility for saying, ‘well actually I think you’re out of order, that’s not appropriate,’ then you must take some responsibility that you’re allowing the situation to continue” (Senior Manager)

Voluntary Sector Managers felt that they take a lead in user involvement anyway and would continue to encourage it because “it’s what your ethos is all about” (Voluntary Sector Manager).

#### **4.4.2 Overcoming Practical Barriers to Involvement**

Most of the barriers to involvement which participants identified were practical in nature and so it is perhaps no surprise that most of the remedies they suggested were aimed at addressing practical issues.

##### **4.4.2.1 Changing the Way in which Meetings are Held.**

Changes to some aspects of how meetings were held was cited by several participants as a way of encouraging involvement. One service user felt that it would be beneficial for users attending meetings to have

“an opportunity to speak to other professionals before and ask questions afterwards as well.” (Service User)

By implication many of the criticisms of how meetings are held suggest remedies e.g. changing the time and location of some meetings, having a break in a lengthy meeting as well as more attempts at using less jargon might all serve to make meetings more user friendly.

#### **4.4.2.2 A Change in the Benefits System**

The Greenlights group were particularly keen on seeing a change in the Benefits System, which would enable them to receive payments for their involvement without losing benefits. This was in noticeable contrast to the MIND user group, who were not interested in payments for involvement. One Greenlights member explained why they felt payment was important

“You feel like you’re worth something, it’s like you’ve earned it and you’re responsible for what you’ve done and you’ve done it properly. You’ve come into that meeting and you’ve talked about it and you’ve done a proper job of it ...and so you feel valued.” (Service User)

The MIND group were keen on the idea of employing service users and ex-service users however, particularly at GPs surgeries ‘to talk things over with’ prior to seeing the doctor. They felt it might solve the problem and help them to avoid being prescribed drugs.

#### **4.4.2.3 The Use of Direct Payments**

Direct Payments are a relatively new development in social care provision, whereby an individual can have their needs assessed and receive the money equivalent of the costs of the service which might have fitted their needs, in order to employ someone or access a facility which would meet their needs in a way they choose and control. Peck et al (2002) place Direct Payments in the User in control of care planning box in their matrix of Involvement as outlined in the review of literature and subsequently adapted for this research. In Redcar and Cleveland there are currently no mental health service users in receipt of Direct Payments, but as one senior manager stated,

“Using Direct Payments would be a bit more imaginative and innovative in care planning, but unless we can inform service users that that’s perhaps the way forward...then it’s easier to do it from a pick – list (of services)” (Senior Manager)

#### **4.4.3 Future Developments**

All participants agreed that service user involvement would in future be a permanent feature in mental health, but that it still had a long way to go. Ultimately it was hoped by many that it would simply become unremarkable.

“Service users just want to be an accepted part of mental health, just always come along, that it’s just normal to have service users there.

It should be accepted that they're always there and it's a normal expectation." (Service User)

"I'd like to see a time when our strategies, our plans don't say 'increase service user involvement' not because we've got to the point we think we should be at, but because it's so natural that you don't have to." (Senior Manager)

True partnership might involve

"When we say we're going to develop a service, we say who's best to develop and then lead and run that service, not automatically assume it's going to be the vol. Sector or the stat. Sector, it could actually be service users and it's for them to involve us then." (Senior Manager)

In the meantime however, at least one service user felt that a rethink is required

"We need to revisit the whole question of service user involvement in the Locality and I think that the development work that has gone on so far has brought results- it has opened up new avenues and set professionals up thinking about relationships with users and user organisations and it has increased the confidence of quite a few service users and got them thinking about involvement and quite enthusiastic about it, but I still feel like setting up the Greenlights group was only supposed to be a small part of the programme of work and I think that seems to have become the focus and I really want to just take another look at what else we could try and do." (Service User)

Chapter 5 below draws together conclusions about user involvement, and offers recommendations for the future.

## **CHAPTER 5 CONCLUSIONS AND RECOMMENDATIONS**

### **5.1 Conclusions**

The purpose of this study, as set out in Chapter One, is 'to determine how developed the levels of service user involvement are in mental health services and to examine factors constraining progress and how these might be overcome'. A secondary aim is to explore what constitutes 'meaningful' involvement for users. The literature review suggested that constraining factors operated at individual, organisational and societal levels and that many writers and user groups had developed ideas as to how to address these constraints. The review informed the research methods adopted in this study, and indicated some potentially useful lines of questioning to pursue.

Before considering the findings in relation to the implementation of user involvement, it is necessary to review the findings in relation to the nature of 'meaningful' involvement, as it is important that user engagement is of a high quality, not simply widespread. Much of the academic literature, discussed in Chapter Two, debates the issue of at which point on a 'ladder of participation' any 'real' involvement could be said to start; a valid approach based on an analysis of power relationships between users and professionals. However, this study, whilst examining power issues, also indicates that meaningful involvement can take place much lower down the spectrum than a simple power analysis would suggest.

Meaningful involvement was seen by participants as involving being valued, being listened to, being respected and having one's views given equal weight to those of all participants in, for example, a meeting. This did not necessarily mean that users' ideas would always be acted upon, but rather that they were taken seriously and, if adopting their ideas was not practical for whatever reason, that they were given a reasonable explanation as to why. Although it was not the purpose of involvement, an increase in user confidence often ensued from such engagement and cannot be discounted in terms of individual meanings. Participants also indicated that involvement held more meaning if it was relevant to their own experience e.g. being involved in running a service they also use, or being involved in their own care.

In order to look at the extent of service user involvement in the Locality, the device of a matrix of involvement was used (see Fig 1.1). It will be remembered from Chapter One that a Locality committed to user involvement could be expected to have activity in most of the compartments of the matrix. This study indicates that Redcar and Cleveland do indeed have activity in all compartments, with the exception of the 'User as agent in control of planning and services' box. However, it is also apparent from the findings that some aspects of user involvement are more highly developed than others and that some areas require more attention.

User involvement in care planning was considered by professionals to be the cornerstone of good practice in care co-ordination. Unfortunately this study did not involve enough participants who were subject to CPA for levels of involvement to be adequately assessed, although the few users who were on CPA said that they felt involved. The survey results would seem to contradict that finding to an extent, but as mentioned earlier, this survey was flawed in design and execution. There would appear to be some weaknesses apparent for all the survey's flaws, particularly in information-giving, an area which can have far-reaching consequences in terms of user empowerment. Users indicated that the quality of their care was very much dependant on individual staff. Further research to look at users experience of care co-ordination is likely to prove fruitful, with qualitative methods being employed, including face-to-face interviews. It can be claimed from the findings however that the Locality has a marked weakness in giving control of care planning to service users, evidenced by the fact that there are no mental health service users who are using Direct Payments.

In the delivery of services, there is much evidence of user involvement, extending to genuine user control in areas such as day services, advocacy and newsletters. Consultation is widespread, as is information-giving.

In the service planning area, activity tends to cluster around the consultation level, particularly in the voluntary sector, although the statutory sector does show a commitment to involving users in service planning.

Participants highlighted various factors which may be inhibiting user involvement locally. These barriers operate at individual, organisational and societal levels. Individual barriers, such as the nature of a person's illness, may be difficult to address, but it is important for professionals to be aware that they operate when trying to develop user involvement. The findings suggest that many constraints are operating at the organisational level, such as the way meetings are held, reaching a wider range of users, overcoming the potential loss of welfare benefits and the attitudes of both professionals and users. However, many of these concerns imply their own solutions, as will be explored later in this Chapter. Further research would be useful to examine any differences between the expressed views of professionals and their practice, given the high level of expressed commitment to user involvement evident in the responses of professionals and the feelings of some users that sometimes their involvement was acceptable only if they 'played the game'. This is not to suggest that professionals are necessarily aware of any discrepancies between their views and their behaviour. Societal attitudes to mental illness represent the final constraint on involvement which has been highlighted by this study and this is perhaps the most difficult to address, and also the one most crucial to the ability of individuals with mental health problems realising the rights of their citizenship.

Respondents developed some ideas for overcoming barriers to involvement, with a clear role for care co-ordinators as proactive agents in promoting involvement emerging as one theme. Practical suggestions were also made regarding the holding of meetings, changing the Benefits system and implementing Direct Payments.

The study has demonstrated that the Redcar and Cleveland Locality is striving to involve its service users in all aspects of its services. It is also apparent that far from only being involved in consultation, there has been some real progress towards users running services, working to combat stigma and in the process feeling valued and more confident. However, the evidence indicates that the Locality still has some way to go to empower users in influencing their own care and to reach a stage where both users and professionals feel entirely comfortable with user involvement. The next section sets out a set of recommendations which have been developed to further this process.

## **5.2 Recommendations**

### **1. Improve User Involvement in Care Co-ordination.**

Users should be given more information regarding their illness and the range of treatments available. This could be achieved by a combination of the development of user information packs and face-to-face discussions.

Users should be more involved in all aspects of care co-ordination and greater use of advocates should be encouraged. Inevitably this will fall to the individual care co-ordinator and in the case of psychiatrists, who have caseloads of over 100 patients, assistance with this may be required from other staff. Arguably it is at this level that user involvement can have the greatest and most beneficial effect on the life of the service user and it should remain a priority.

### **2. Introduction of Empowering Mechanisms.**

Following on from this, there should be a drive to introduce empowering mechanisms such as Direct Payments into the Care Co-ordination process. This will involve marketing the possibilities to users and professionals, with further training required for professionals. The offering of Direct Payments should be a formalised part of Care Co-ordination when considering with users how to meet their needs. This person-centred approach will increase choice and control and enable users to access community resources should they wish, a more socially inclusive road to recovery . There will be resource implications which will need to be resolved, but by making the number of people in receipt of Direct Payments a performance indicator, the Government have signalled that the implementation is not optional for Local Authorities.

### **3. A Commitment to Service User Development Work.**

Statutory services should commit ongoing funding to user development work, by continuing to fund a Service User Development post, with the ultimate goal of employing a user in this role. The management of the post should be reviewed, to facilitate more autonomy of action and enable a united user group to develop which is not tied to one service provider. A continued dedicated budget for user involvement could target outreach work with people outside of day services in order to engage a broader range of people. Care Co-ordinators will also have a role in this 'outreach', both in information giving and reassuring users that they

will not be penalised for speaking up. Ideally a meeting place independent of mental health services should be sought.

#### **4. Capacity Building Among Service Users.**

Following on from the aim of employing a service user as Development Worker, capacity building in the user group needs to continue in order to train successors and prevent the it being dependant on one or two possibly fragile individuals. More group members should be able to access the TNEY Leadership Development Programme, to increase their confidence and skills and to address some of the issues they raised about working in complex organisations.

#### **5. Re-engineering Meetings.**

Professionals should re-examine the process of how meetings are held. User involvement needs to be embedded in the structure of how work is undertaken. Consideration should be given to using non-mental health venues (Social Services have some venues which are available for no or little charge). Flexibility regarding the timing of meetings, sending out agendas in plenty of time, and 'mentoring' for service users being routine rather than the exception should all be in place. Breaks in lengthy meetings should be introduced, so that individuals with concentration problems are not made to feel lacking in any way.

#### **6. Action Against Stigmatisation of Mental Illness.**

User groups and professionals should continue to work together to combat the stigma of mental illness and to pressure the Government into a reform of the Benefits System, which will enable the mentally ill to be paid for involvement in services and to return to work gradually following a period of illness.

Although there are resource implications from these recommendations, they are not so great as to render them unachievable. User involvement in the Locality is developing well and further work needs to be done if it is to "enter the bloodstream" as called for in a recent CHI audit. (CHI (2004) in SSI op. cit. (2004))

## References

- Arnstein, S.R. (1969) 'A Ladder of Citizen Participation'. *Journal of the American Institute of Planners* 35 p216-224.
- Audit Commission (1999) '*Listen UP! Effective Community Consultation*'.
- Audit Commission (2003) '*User Focus & Citizen Engagement: Learning from Comprehensive Performance Assessment brief 4*'.
- Bailey, D. (1997) 'Letter from Birmingham: What is the way Forward for a user-led approach to the delivery of mental health services in primary care?' *Journal of Mental Health* 6:1 (p101-105)
- Barnes, D., Carpenter, J., Bailey, D. (2000) 'Partnerships with service users in interprofessional education for community mental health: a case study'. *Journal of Interprofessional Care* Vol. 14 No. 2 p189 –199
- Barnes, M & Bowl, R. (2001) '*Taking Over the Asylum: Empowerment and Mental Health*'. Palgrave. Basingstoke.
- Barnes, M. & Shardlow, P. (1997) 'From Passive Recipient to Active Citizen: Participation in Mental Health User Groups.' *Journal of Mental Health* 6:3 p289-300
- Bowl, R. (1996) 'Involving Service Users in Mental Health Services: Social Services Departments and the National Health Service and Community Care Act 1990'. *Journal of Mental Health* 5:3 p287 – 303
- Campbell, P. & Lindow, V. (1997) 'Changing Practice, Mental health nursing and user empowerment'. MIND/RCN p6
- Campbell, P. (2001) 'The role of users of psychiatric services in service development – influence not power'. *Psychiatric Bulletin* 25 p 87- 88.
- Cheston, R., Bender, M. & Byatt, S. (2000) 'Involving people who have dementia in the evaluation of services: A review.' *Journal of Mental Health* 9:5 p471 – 479.
- Corrigan, P. & Joyce, P. (1997) 'Reconstructing Public Management : A new responsibility for the public and a case study of local government'. *International Journal of Public Sector Management* Vol. 10 No. 6 p417 –432.
- Crawford, M. (2001) 'Involving users in the development of psychiatric services – no longer an option'. *Psychiatric Bulletin* 25 p 84 – 86.
- Denzin, N.K. & Lincoln, Y.S. (1998) '*Strategies of Qualitative Enquiry*'. Sage, Ca.
- Department of Health (1999) '*National Service Framework for mental Health : Modern Standards and Service Models*'.

Department of Health (2001) *'Involving Patients and the Public in Healthcare – A discussion document'*.

Dey, I. (1993) *'Qualitative Data Analysis: A user friendly guide for social scientists'*. Routledge. London.

Harrison, S. & Mort, M. (1998) 'Which Champions, Which People? Public and user involvement in health care as a technology of legitimation.' *Social Policy and Administration*. Vol.32 No. 1. pp 60 - 70.

*Health and Social Care Act* (2001) Command 15. The Stationery Office, London.

Hickey, G. & Kipping, C. (1990) 'Exploring the concept of user involvement in mental health through a participation continuum'. *Journal of Clinical Nursing* Vol. 7 (1) p 83–88.

Hoggett, P. (1992) 'The Politics of Empowerment', *Going Local* 19 p18-19

Hostick, T. (1998) 'Developing user involvement in mental health services'. *Journal of Psychiatric and Mental Health Nursing* 5 p 439 – 444

Joseph Rowntree Foundation (2003) *'Shaping our Lives from outset to outcome: What people think of the social care services they use'*.

Joseph Rowntree Foundation *'The Experiences of mental health service users as mental health professionals'*.

Kelly, A. (1991) 'The enterprise culture an the welfare state: restructuring the management of health and personal social services.' in *'Developing the Enterprise Culture'* Barrows, R. (ed.) Routledge London.

Krueger, R.A.(1998) *'Developing Questions for Focus Groups'* Sage. London.

Marshall, C. & Rossman, G.B. (1999) *'Designing Qualitative Research'* Sage. London.

Miles, M.B. & Huberman, A.M. (1994) *'Qualitative Data Analysis'* Sage, Ca.

MIND *'User Empowerment'* [www.mind.org.uk](http://www.mind.org.uk) downloaded 19/8/03  
Info/factsheets

Morgan, D.L. (1998) *'The Focus Group Guidebook'* Sage. Ca.

National Institute for Mental Health in England (NIMHE) (2003) *'Cases for Change: User Involvement'*. Department of Health.

National Schizophrenia Fellowship (1997) *'How to involve service users and carers in planning, running and monitoring care services and curriculum development.'*

*NHS & Community Care Act* (1990) Command 19. Stationery Office , London.

NHS Plan (2000) Command 4818-1, Stationery Office, London.

Peck, E., Gulliver, P. & Towel, D. (2002) 'Information, consultation or control: user involvement in mental health services in England at the turn of the century'. *Journal of Mental Health* Vol. 11:2 pp 441 – 451.

Perkins, R., Buckfield, R. & Choy, D. (1997) 'Access to employment: A supported employment project to enable mental health service users to obtain jobs within mental health teams'. *Journal of Mental Health* Vol. 6:3 pp 307 – 318.

Pierre, S.A. (2000) 'Psychiatry and Citizenship: the Liverpool black mental health service users' perspective.' *Journal of Psychiatric and Mental Health Nursing*. 7 pp 249-257

Pilgrim, D. & Waldron, L. (1998) 'User involvement in mental health service development: How far can it go?' *Journal of Mental Health* Vol. 7:1 pp 95-104.

Reason, P. & Bradbury, H. (eds.)(2001) '*Handbook of Action Research: Participative Inquiry & Practice*'. Sage. London.

Robert, G., Hardacre, J., Locock, L., Bate, P. & Glasby, J. (2003) 'Redesigning mental health services: Lessons on user involvement from the Mental Health Collaborative'. *Health Expectations* 6. pp 60 – 71.

Ryan, T. & Bamber, C. (2002) 'A survey of policy and practice on expenses and other payments to mental health service users and carers participating in service development'. *Journal of Mental Health* Vol. 11:6 pp 635 – 644.

Scottish Development Centre for Mental Health (2001) '*Route Map to User and Carer Participation*'.

Simpson, E. & House, A. (2002) 'Involving users in the delivery and evaluation of mental health services: systematic review'. *BMJ* Vol. 325 30<sup>th</sup> Nov.2002 p1265.

Simpson, E.L., House, A.O. & Barkham, M. (2002) '*A Guide to involving service users, ex-users and carers in mental health service planning, delivery or research; a health technology approach*'. Leeds Academic Unit of Psychiatry & Behavioural Sciences, University of Leeds.

STAMP Revisited, [www.stamprevisited.com](http://www.stamprevisited.com), accessed on 27/07/04

Stewart, D.W. & Kamins, M.A. (1993) '*Secondary Research: Information Sources & Methods*'. Sage. London.

Summers, A. (2003) 'Involving users in the development of mental health services : A study of psychiatrists' views'. *Journal of Mental Health* Vol. 12:2 pp161-174

Truman, C. & Raine, P. (2002) 'Experience and meaning of service user involvement: some explorations from a community mental health project'. *Health & Social Care in the Community* Vol. 10:3 pp136-143

Wallcraft, J., Read, J. & Sweeney, A. (2003) *'On Our Own Terms: Users and survivors of mental health services working together for support and change'*. Sainsbury Centre for Mental Health.

## Appendix

## APENDIX ONE: FOCUS GROUP CONSENT AGREEMENT

I, \_\_\_\_\_, agree to participate in this research project on Service User Involvement in Redcar and Cleveland Mental Health Services that is being conducted by Julia Svennevig from Social Services.

I understand that the purpose of this study is to hold a group interview to find out about user involvement; we will discuss our general ideas about involvement.

I understand that the study involves a focus group interview that lasts no more than 2 hours, which will be recorded.

I understand that my participation in this study is entirely voluntary, and that if I wish to withdraw from the study or to leave, I may do so at any time, and that I do not need to give any reasons or explanations for doing so. If I do withdraw from the study, I understand that this will have no effect on my relationship with Social Services or any other organization or agency.

I understand that because of this study, there could be violations of my privacy. To prevent violations of my own or others' privacy, I have been asked not to talk about any of my own or others' private experiences that I would consider too personal or revealing.

I also understand that all the information I give will be kept confidential and that the names of all the people in the study will be kept confidential.

The researcher has agreed to answer any questions I may have about the study and what I am expected to do.

I have read and understand this information and I agree to take part in the study.

\_\_\_\_\_  
today's date

\_\_\_\_\_  
your signature