

*National Institute for
Mental Health in England*

Cases for Change

User Involvement



Cases for Change

Mental health services in England are experiencing a period of unprecedented change. The pace of this change is potentially matched only by the pace at which information about both effective and less effective practice in mental health care is emerging. Over the past five years an incredible wealth of published literature has continued to remind all those engaged in developing mental health services of the reasons why fundamental change is necessary and of how services might be improved to better meet the needs of service users.

In addition to the evidence emerging from the research literature, it is important to recognise the role that publications appearing beyond the peer-reviewed journals have also had in informing the many cases for change that exist in adult mental health care today. These include publications reporting non-research based service reviews and the expert opinion of groups and organisations representing the interests of mental health service users, carers and professionals.

For those engaged daily in supporting change in local mental health services it can be difficult to feel well informed of the context of evidence and opinion within which current mental health policy has been established. With this in mind, in late 2001 the National Institute for Mental Health in England (NIMHE) commissioned a review of recent literature on adult mental health services with a view to producing an accessible summary of the emerging cases for change.

Cases for Change comprises ten booklets.

- **Introduction:** describes the background and methodology of the review and also summarises the findings and suggests areas for future research/policy development.
- **Policy Context:** describes the context of the review with an overview of recent mental health policy.

The following seven booklets each consider a different aspect of mental health service provision:

- **Primary Care**
- **Community Services**
- **Hospital Services**
- **Forensic Mental Health Services**
- **Partnership Working Across Health & Social Care**
- **User Involvement**
- **Anti-discriminatory Practice**
- **Emerging Areas of Service Provision:** reviews the literature that does not fit neatly into any of the previous topics.

The review collates evidence from over 650 documents published between January 1997 and February 2002 concerning adult mental health service delivery and/or policy in England. With the information collected synthesised into a number of key themes or issues, the review aims to describe how we got to where we are today and sets out the cases for change from the evidence base.

The articles highlighted at the beginning of each booklet as The Nature of the Evidence are those that are particularly relevant to the cases for change cited in the booklet concerned. Each document within the review has been classified using the "hierarchy of evidence" adopted in the *National Service Framework for Mental Health (NSF)* (Department of Health, 1999a):

- Type 1 evidence represents at least one good systematic review, including at least one randomised controlled trial.
- Type 2 evidence represents at least one good randomised controlled trial.
- Type 3 evidence represents at least one well-designed intervention study without randomisation.
- Type 4 evidence represents at least one well-designed observational study.
- Type 5 evidence represents expert opinion, including the opinion of services users and carers.

At the end of each of the main booklets, there are critical commentaries by service users and practitioners/managers/policy analysts from across England. These commentaries are intended to emphasise that different groups of people have different priorities and identify different cases for change. All contributors have been encouraged to be as challenging as possible and, where they disagree with interpretations, to say so.

Each booklet can be read independently or alongside one another to bring together a full picture of the development of mental health services. We hope this will be helpful in enhancing our understanding of the history as well as emphasising the need to develop future individual services within the context of an integrated system of care and support.

Cases for Change should be seen as a starting point and as a means to an end rather than an end in itself. By summarising the key issues that have emerged from the literature and by emphasising the diversity of opinion that exists within mental health services, Cases for Change may help to encourage debate about the best way forward and the way in which different view points can be balanced to achieve mutually beneficial outcomes.

Cases for Change has been written by a multi-disciplinary research team based at

the University of Birmingham with the active support and encouragement of Susannah Rix at NIMHE Eastern, the guidance of the Expert Panel, and service users and practitioners who have provided written commentaries for the main sections of the review. Our thanks also to colleagues in the mental health group at the Department of Health for their editorial input to help finalise the publication.

The research team comprised:

- Jon Glasby, a qualified social worker and a lecturer at the Health Services Management Centre.
- Helen Lester, a GP, national primary care career scientist and Co-Director of the University of Birmingham's Interdisciplinary Centre for Mental Health.
- James Briscoe, a consultant psychiatrist and senior lecturer in the University of Birmingham's Department of Primary Care.
- Marion Clark, a former teacher who worked on this study as a user consultant.
- Steve Rose, Library and Information Services Manager at the Health Services Management Centre at the time of this review and now Health Care Libraries Manager, University of Oxford.
- Liz England, a clinical research fellow in the University of Birmingham's Department of Primary Care.

Four Seasons

These original artworks were designed and painted by a team at The Hollies in Ipswich, Suffolk. Working together the group generates ideas, energy and input. The community spirit engendered provides a platform that allows creativity to shine through. The group experience builds confidence and develops a sense of esteem. *"This kind of work may not cure our problems, but this is the first year I have not been admitted to hospital".*

The Hollies is a Social Enterprise developing meaningful work opportunities for people who have used mental health services. Social Enterprise can and does create real jobs. The pictures illustrate a theme of constant change and renewal in nature. They reflect the changes that can evolve through Social Enterprise and working together.

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The Nature of the Evidence

	Number of Articles
Type I	0
Type II	0
Type III	0
Type IV	9
Type V	60

Background

Traditionally, welfare provision in the UK has been predominantly paternalistic, with interventions carried out on service users by a range of welfare professionals, and with the latter seen very much as the 'experts.' As a result, professionals such as doctors, nurses and teachers have tended to occupy positions of authority and status, with users deferring to their specialist knowledge and expertise. This is encapsulated in the phrase "doctor knows best," implying that the intensive training which a particular professional has undertaken equips them to identify and respond to a potential problem with little or no input from the individual actually experiencing the problem.

More recently, this has begun to change as a result of two separate but inter-related developments:

1. The growth of consumerism as a guiding principle within public services.
2. The emergence of a number of service user movements campaigning for more responsive services, a greater say in their own care and greater acceptance by wider society.

During the 1980s and early 1990s, public services became increasingly dominated by the concept of consumerism. Borrowing the language of the private sector and the market, users of services were increasingly seen as customers who could exercise choice about the type of care they received and, if dissatisfied, could take their custom elsewhere. In many ways, this was motivated by the political ideology of the then Conservative government, which emphasised the need to promote individual choice, to roll back the frontiers of the welfare state and to expand the role of the private and voluntary sectors in areas traditionally dominated by public provision. Unfortunately, this emphasis on

consumerism has been demonstrated to be inadequate when applied to a number of health and social services. As Barnes (1997, p.34) has suggested, consumerism depends on a number of essential preconditions:

- Alternatives need to exist.
- The person concerned needs access to information not only about alternatives, but also about characteristics of alternatives which might suggest that they would overcome dissatisfaction with existing services, but also not substitute new for existing problems.
- Moving from one option to another should be practically possible.
- Moving from one option to another should not of itself generate damaging disruption.

As Barnes continues: "If one considers the circumstances in which most people use health and social care services, it is clear that all these circumstances will rarely apply."

Of course, these criticisms of consumerism are particularly relevant to mental health services, where the concept of a person who can potentially be detained and medicated against their will as a 'customer' is difficult to sustain (Godfrey and Wistow, 1997).

Despite its limitations, the emphasis of consumerism on individual choice and on services being more responsive to the needs of users has found support from the growing number of user organisations campaigning for changes in service provision. In a range of areas, groups of people with physical impairments, mental

health problems and learning difficulties have been at the forefront of attempts to reform traditional services and to promote the rights of individual service users to high quality, responsive and effective services that genuinely meet people's needs (see Barnes, 1997 for further details). Drawing strength from the civil rights movement, user movements have tended to campaign for reform not on the basis that they will take their 'custom' away if dissatisfied, but on the grounds that every individual is a citizen with a series of political, civil and social rights (see figure 1). As Peck and Barker (1997, p.269) explain:

"It was in 1985 that patients' councils in psychiatric services and mental health advocacy projects began to develop in Britain, adopting an approach which broadly aimed to change mental health services from the inside through dialogue and discussion. In the same year, Survivors Speak Out was formed, which, as the name implies, took a more campaigning stance... Of course, the user movement, as it had become widely known by the late 1980s, did exist prior to 1985. Two small groups were already well established: the British Network for Alternatives to Psychiatry, an alliance of patients and professionals sympathetic to an anti-psychiatry perspective; and the Campaign Against Psychiatric Oppression, consisting mainly of patients. These early groups, and many of the individuals who became involved in the user movement in the mid-1980s, had views that were rooted in the social movements of the 1960 and 1970s. Drawing on perspectives from the civil rights movement in the US, as well as

Figure 1 Citizenship

"The status of 'citizen' is a disputed one in the UK because of the absence of a formal constitution. Nevertheless, certain rights are assumed to attach to membership of a political community, irrespective of formal rights enshrined in a constitution. Three types of citizenship rights were defined by Marshall (1950):

- *Legal or civil rights: those which enable the individual to participate freely in the life of the community. These rights include property and contractual rights; rights to freedom of thought, freedom of speech, religious practice, assembly and association.*
- *Political rights: those which entitle the citizen to participate in the government of the community: the right to vote is the most obvious.*
- *Social and economic rights: those intended to enable the individual to participate in the general wellbeing of the community. They include rights to health care, education and welfare. While Marshall considered these rights to be part of what being a citizen means in the twentieth century, they are not defined as entitlements in welfare legislation. Thus they are continually subject to the exercise of discretion on the part of gatekeepers to services."*

(Barnes and Shardlow, 1997, p.293)

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critiques of psychiatry itself (anti-psychiatry, deinstitutionalisation, labelling theory and normalisation), users and their allies started to use consciousness-raising methods in relation to mental health. This approach sought to place the personal stories of mental health users into a wider political context. Users started to develop collective action to bring about change. This strand has continued, for instance with Pilgrim and Rogers (1993) noting 'interest in users campaigning collectively, as a new social movement'.

As a result of consumerism and of action by user groups, public services are now much more responsive to the needs and rights of individual users than they have been in the past. Often, there is a recognition that services should seek wherever possible to meet the individual needs of service users and not simply respond to all users in the same way (the 'one size fits all' approach). At the same time, there is a growing acceptance that many service users want a greater say in how their care is provided and have a right to be consulted about the nature and type of services they receive. This has led to considerable activity in welfare services and to a range of attempts to involve users, not only in decisions about their own care, but also in service design and planning. In many ways, indeed, 'user involvement' appears regularly in policy documents, in mission statements and in the academic literature. As Campell (1997, p.31; 2000, p.87) observes:

"Anybody assessing the involvement of users in mental health services must acknowledge the great changes that have taken place in the past 15 years. In the early 1980s few, if any, mental health service users were directly involved in the planning, managing and monitoring of services. Independent mental health advocacy was in its infancy and the training of mental health workers by service users was extremely rare. There were less than half a dozen user-led organisations and politicians complained about the difficulties involved in hearing the voice of the consumer of care. Now... service user involvement is extensive. The voices of a significant number of service users can be heard through the hundreds of local user-led action groups that have been established in the last 10 years and via voluntary organisations, such as Mind and the National Schizophrenia Fellowship, that have supported the growth of their own user-only networks."

"Moreover, the debate surrounding service user involvement seems to have moved

some way beyond arguments about whether service users have a right to be involved or have anything at all useful to contribute to issues about the how, when and where of involvement."

Despite such significant progress, however, there is considerable evidence to suggest that the often very good intentions of service providers can sometimes fail to move beyond rhetoric into reality. We return to this issue later in the chapter.

Although user involvement is a key concept in current health and social care services, it is rarely defined and is often used to encapsulate a range of different ideas and activities (see Braye, 2000 for a brief overview):

- Service users may be involved in decisions about their own care or in planning services more generally.
- People may be involved on an individual basis or can work with other users to engage in collective activity.
- There are different degrees of involvement ranging from simple information giving and consultation on the one hand through to partnerships between professionals and users and user-led services on the other.

A useful model for encapsulating this

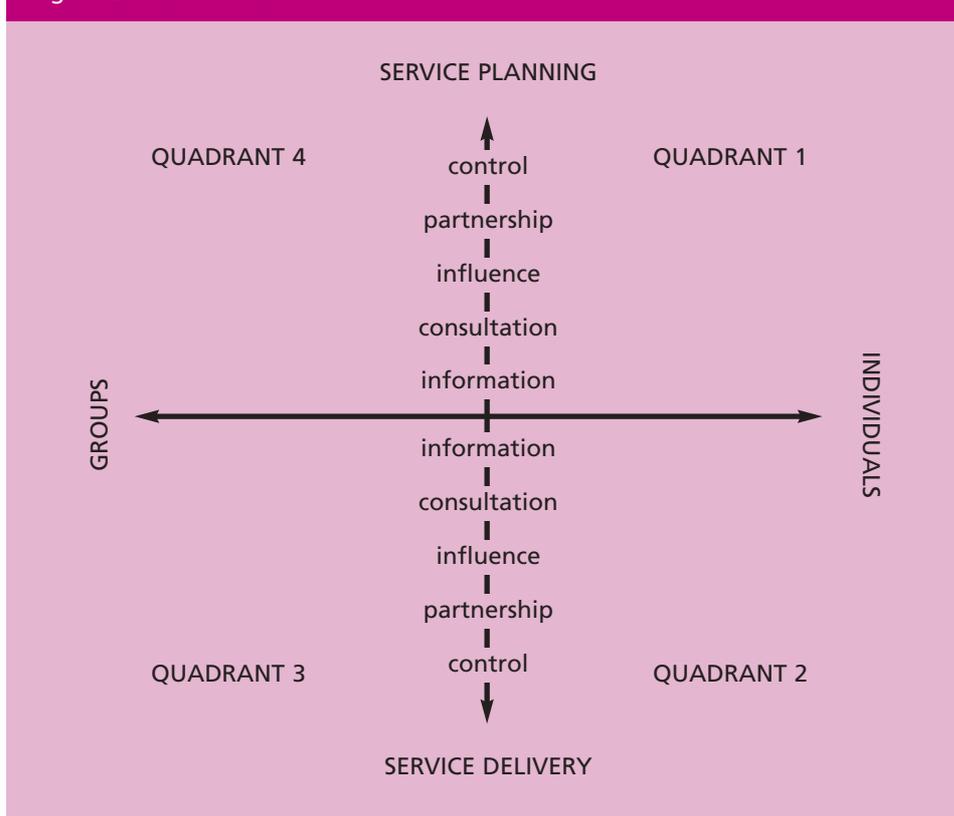
complexity is provided by Hoggett (1992, p.19, quoted in Means and Smith, 1998, p.89) (see figure 2). This seeks to distinguish between the degree of participation/control available and whether the user is involved as an individual or via collective action. For example:

- Is the user involved in decisions about their own care or service plan (quadrant 1)?
- Does the user have any influence over the way that these services are then delivered (quadrant 2)?
- If the user is part of a group which receives a particular service, to what extent is the group able to influence the way in which the service is provided (quadrant 3)?
- The user may be one of many living in the area with similar needs and problems. To what extent is the group involved in the service planning process (quadrant 4)?

Closely linked to user involvement is the notion of empowerment. This, again, is a complex concept that is difficult to define, but, at its most basic, involves:

- Professionals recognising that their training, their status as salaried workers, their control of public resources places

Figure 2 User Involvement



them in a more powerful position than the service users with whom they work.

- Professionals being prepared to relinquish a degree of their own power and working with service users rather than for them.
- Professionals enabling service users to have greater choice and control over their own lives.
- Not only listening to but responding to users' views.

As Means and Smith (1998, p.71) explain:

"There is no simple answer as to what does and what does not represent user empowerment, since it is a contested concept. However, most would argue that it involves users taking or being given more power over decisions affecting their welfare."

Cases for Change

Although mental health services have faced the same pressure to involve and empower service users, they face a number of distinctive features that have made genuine involvement difficult to achieve. In particular, the Cases for Change literature sheds light on three key issues:

- The benefits of user involvement.
- Barriers to greater involvement.
- Methods of overcoming these barriers.

The benefits of user involvement:

The Cases for Change literature is almost unanimous in its belief that user involvement is a worthwhile activity with a range of benefits (both practical and ethical). These include five main issues:

1. There is a widespread recognition that service users are experts in their experience, with an in-depth knowledge of mental health services and of living with a mental health problem. By definition, no one else – no matter how well trained or qualified – can possibly have had the same experience of the onset of mental illness, the same initial contact with services or the same journey through the mental health system. These experiences are an important resource that can help to improve individual packages of care as well as services more generally (see figure 3).
2. As a result of their experience of mental illness, service users have developed a range of coping mechanisms and survival strategies that help them to

Figure 3 Service Users as Experts

"From a user perspective then, a key issue posed for mental health professionals is the concept of users as 'experts' in their own illness and seeking to be active participants in its management. It suggests the need for mental health staff to seek out and understand users' experience of illness and the strategies they and those close to them, have developed to manage it. It presents a picture of a potential partnership involving both lay and professional knowledge and expertise where mental health specialists also harness and support existing helping processes."

(Godfrey, 1999, p.18)

"Patient know themselves best and should be experts in their care."

(McDougall, 1997, p.4)

"We are all the primary experts on our own mental health, and about what works for us. We are more than the sum of our individual problems and of the services that we use. We can and should value and appreciate the coping strategies we have developed for ourselves. We have the right to expect that mental health professionals will listen to us and to our views about treatments and services, and take account of those views."

(Mental Health Foundation, 1997, p.4)

manage their mental health problems and go about their daily lives as best they can. Thus, Faulkner and Layzell (2000) highlight the way in which people with mental health problems have developed their own Strategies for Living with mental illness, while Borrill (2000) emphasises the way in which users can predict when they are about to become unwell and formulate appropriate responses at an early stage. If mental health practitioners tap into this expertise, they make their own jobs much easier by focusing on users' strengths (see figure 3).

3. Service users and mental health workers often have very different perspectives about care. As a result, involving users can provide extremely rich data which prompts practitioners to re-evaluate their work, challenges traditional assumptions and highlights key priorities which users would like to see addressed. While many workers may be focused on managing a heavy case load or introducing new service structures, users often value very different aspects of service provision. Recurrent themes include:
 - The importance of information and of feeling that someone is listening (see, for example, Bailey, 1997; Carpenter and Sbaraini, 1997).
 - The need for holistic approaches which look beyond people's mental health and encompass every aspect of people's lives (including the material, emotional and spiritual) (see, for example, Beresford, 2000; Mental Health Foundation, 1997).

A good example is provided by Hannigan et al (1997), whose focus groups with service users in London identified the importance of family and intimate relationships, friendships, interpersonal relationships with mental health professionals, community presence, work, social/leisure activities, housing, money and discrimination – all issues that are much broader than the service-focused agenda of many mental health agencies.

Another useful illustration is provided by Lindow (1999, p.154), who highlights the way in which users and service providers may have very different priorities:

"Our discussion are seldom about new styles of management, or changes in service organisations: I have heard little interest [among users] in the idea of a GP-led National Health Service. There is, rather, much discussion of poverty, employment, housing; about services that control and rob our experiences of meaning and about dangerous treatment."

4. Users have been able to develop alternative approaches to mental health that might help to complement existing services or suggest new ways of thinking about mental health. Examples include:
 - The importance of alternative and complementary therapies (Faulkner and Layzell, 2000; Mental Health Foundation, 1997).

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- Crisis cards and advance directive schemes so that people can specify in advance what they want to happen if they become unwell (Beresford, 2000; Sutherby et al., 1999). Thus, Sutherby and Szmukler's (1998) survey of national and local user groups found a number of examples of crisis cards and self-help initiatives which sought to provide information about current care and treatment plans, identify what may help in a crisis, nominate an advocate in case of an emergency and specify advance plans for care in a crisis.

- The recovery model (see figure 4).

5. User involvement can be therapeutic, enabling people to feel that they are being listened to and that their contribution is being valued. Helping to shape services – particular when users work together collectively - can also

help people to increase their confidence, raise self-esteem and develop new skills. As Barnes and Shardlow (1997, pp.297-298) explain:

"In different ways user groups provide 'safe environments' in which sometimes fragile identities can be supported, and confidence and skills can be developed. [During our research] we heard many testimonies of the way in which involvement... had built personal confidence and which had enabled people to turn damaging experiences into a positive outcome... Participation within a group quite literally gives people a 'voice' and as confidence develops they are able to play a role in organising the group, in planning forums involving service purchasers and providers, and in representing the group at conferences and seminars. Acquiring

new skills can provide a further boost to confidence and self-esteem and can be a springboard to [new] opportunities."

Additional benefits of user involvement are also identified by the National Schizophrenia Fellowship (1997, p3):

- More effective partnerships of care between service users, carers and professionals.
- Better understanding by staff of the effects of disability or illness on service users and their families.
- Better targeted services based on identified needs.
- More likelihood that service users will engage with treatment and care plans.
- Better working relationships between service users, carers and staff.
- Critical light being thrown on the effectiveness of particular interventions.
- Carers and users feeling empowered, confident and valued, thereby making them feel more in control and so enhancing the quality of their lives.

Figure 4 The Recovery Model

There is no clear definition of recovery since inevitably each individual has their own experiences and definition. As Topor (1998, pp.2-3) suggests:

"To recover can mean different things. In contemporary research and among patients themselves, recovery is not regarded as an end-product but as a process - the re-assertion of an independent relationship to the self and one's own life. Some patients recover socially; that is, they may continue to experience certain symptoms of what can be regarded as a mental disorder. Perhaps they still hear voices or have visions, but they are not troubled by them to the same extent nor in the same manner as before. They have found a way to cope with the voices. They may remain in contact with mental health services for support and to receive medication in low doses. They may still receive some support from the social services. But this does not prevent them from living a satisfactory life, having friends and perhaps having a job. Some patients recover totally; that is, they no longer experience any symptoms of disorder nor do they receive any treatment. They live an ordinary life and no longer need to turn to psychiatry or the social services for help to deal with their mental or emotional problems. Recovery seems to be a real possibility, even after years of having a severe mental disorder."

This suggests the need for services that can help the individual to achieve the sort of lifestyle they wish to live. This may mean a shift in emphasis from the traditional concerns of diagnoses and reducing symptoms to what service users often see as their 'real' problems (e.g. being able to participate in society, support themselves and enjoy feelings of well-being).

As Barnes and Bowl (2001, p.95) explain:

"We are reminded of a young male long-term service user with a diagnosis of schizophrenia whose life had been extremely disrupted by his experience of hallucinations and 'thought disorder'. As a consequence he was placed on medication which effectively controlled these symptoms and permitted him to live in the community. This gave him the chance to make relationships and in time he met a young woman and found his first potential partner. This had a very positive impact and brought real quality to his life. However, a side-effect of his medication was that, at least temporarily, he was impotent and eventually this became too big an impediment to the development of the relationship and it was lost. He was devastated and his quality of life nose-dived. Yet his symptoms continued to be controlled - the impact of the psychiatric intervention would register as positive within [traditional psychiatry]."

Barriers to greater involvement:

Despite the benefits of user involvement and despite significant progress in recent years, levels of user involvement remain patchy and there is scope for considerable progress. In South East England, for example, questionnaires and interviews with 109 service users revealed a considerable lack of involvement (see figure 5), while Rose's (2001) work with over 500 users across seven sites found very low levels of involvement in individual care planning and in the planning and delivery of services more generally. In addition, Webb et al's (2000) survey of 503 patients across five NHS Trusts found a lack of involvement in the care planning process and a failure to respond to several prominent and longstanding criticisms from the user movement:

"On the face of it... the results of this study point to the old chestnuts that mental health user campaign groups have raised again and again in the past two decades, and that previous studies have reported on: a lack of information, communication and consultation. It would seem that the National Health Service still has some way to go in meeting these basic principles of good quality care."

In seeking to explain the current limitations of user involvement, the Cases for Change

Figure 5 Users Views about the Level of Involvement

	Yes (%)	No (%)
Have you been asked what you thought about your admission to hospital and/or involvement with services?	31	60
Do you feel you have been encouraged by professionals to say what your aims are for care and treatment?	63	31
Do you feel you have a choice in your care and treatment when in hospital?	32	59
Do you feel you have a choice in your care and treatment when in the community?	76	22

Adapted from Carpenter and Sbaraini, 1997, p.46

literature identifies a number of barriers to further progress:

- First and foremost, studies highlight a widespread lack of information for service users. This includes a lack of information about the nature of people's mental health problems, the side-effects of medication, alternative forms of treatment, mental health law and a range of other issues (see, for example, Bird, 1998; Campbell, 2001; Carpenter and Sbaraini, 1997; Hogman and Sandamas, 1999; Morrissey, 1998; Rose, 2001; Webb et al., 2000). Clearly, accessible information is an essential prerequisite for meaningful involvement and there will be little scope for progress until users are enabled to make informed choices about existing provision. As Rose (2001, p.6) observes:

"Mental health service users need information to make informed choices about their care. Around 50% of [over 500] users interviewed for this work felt they were not getting enough information on a range of issues and therefore felt themselves to be recipients of rather than involved in their mental health care."

- User involvement, if done properly, can be expensive and time consuming (see, for example, Barber, 1998; Campbell, 1997). A good example is provided by Carpenter and Sbaraini (1997, p.27), whose account of user involvement in the care management process identified time constraints as a major barrier:

"The main disadvantage [of user involvement] perceived by staff was that the process took more time than previously. The assessment and planning meetings themselves took between 45 minutes and

one-and-a-half hours, depending on the amount of preparatory work which had been done, the complexity of the user's needs and their ability to contribute to the discussion. In some cases this was longer than the participants and care manager had allowed. To this must be added the time involved explaining the purpose and procedures to the user, liaising with carers and other professionals, and in setting up the meetings themselves. Following the meetings, the forms had to be written out clearly for typing, typed, checked with the user and distributed. In the event that the user's condition had deteriorated severely, or for some reason the care programme had proved difficult to implement, all the preceding work could sometimes be seen by the care manager as time wasted."

- Existing mechanisms for involving service users in their own care may be limited in terms of their effectiveness. In particular, a number of commentators raise doubts about the extent to which users are routinely involved in developing their own care plans in conjunction with mental health practitioners. In some studies, indeed, care planning has been seen as little more than a 'paper exercise,' with service users unsure what a care plan is, not knowing who their keyworker is and feeling unable to speak up (see, for example, Campbell, 1997; McDermott, 1998; Rose, 2001; Webb et al., 2000). Other mechanisms for involvement include the complaints processes operated by health and social care agencies, although there is evidence to suggest that many users do not feel able to complain about services due to a lack of knowledge about complaints procedures and a fear of not being listened to or of being branded a

'troublemaker' (Carpenter and Sbaraini, 1997; Rose, 2001).

- Professionals wishing to promote user involvement frequently express concerns about the 'representativeness' of individual service users, sometimes suggesting that particular users may be "too well", "too articulate" or "too vocal" to represent the views of users more generally. While it is important that all users with views to contribute feel able to become more involved, a number of commentators emphasise the danger that the concept of 'representativeness' can be used as a sub-conscious method of resisting user involvement (see figure 6). As Lindow (1999, p.166) responds:

"When workers find what we [users] are saying challenging, the most usual strategy to discredit user voices is to suggest we are not to be listened to because we are too articulate, and not representative. Workers seem to be looking for someone, the 'typical' patient, who is so passive and/or drugged that they comply with their plans. We are developing our own strategies to respond to these challenges in an attempt to reveal to such workers their double standards:

- *We ask how representative are they,*

Figure 6 User Involvement and 'Representativeness'

"Concerns are sometimes expressed about whether those who represent the views of service users do so accurately – how can one know whether or not the views of a service user reflect those of users more generally? This problem is not specific to those representing the views of service users. The same question could be asked of those representing the views of local general practitioners, psychiatrists etc... Some user group representatives... are democratically elected. Others receive training that involves considering one's own views and those of others. Central to the concept of user involvement is the understanding that someone who has experienced services has developed an informed view that is of value to those developing and assessing services. Concern about the representativeness of service users must not be used to undermine the criticisms of service users."

(Crawford, 2001, p.85)

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and the others on the committee? We point out that as they are selected for their expertise and experience, so are we. Indeed, we are more likely to have been selected by a group than they are.

- We ask, would workers send their least articulate colleague to represent their views, or the least confident nurse to negotiate for a change in conditions?
- We ask, if a person's criticisms are valid, what relevance has representativeness?
- We point out that it is very rude to suggest that someone is not a 'proper' service user (that is, so disempowered and/or medicated that they cannot speak). We could ask, but do not, that the challenger produce his or her credentials, their certificates of qualification."

- Many mental health services may not be conducive to user involvement. For some people, mental health services can be experienced as extremely disempowering, with users being compulsorily admitted to hospital and medicated against their will (see, for example, Barnes et al., 2000; Breeze and Repper, 1998; see also figure 7). Users' contributions may also be discounted as a result of their illness or of public attitudes about risk and dangerousness (Godfrey and Wistow, 1997). A good example of the potentially disempowering nature of mental health services comes from Breeze and Repper's (1998) exploratory study of six 'difficult to manage' patients, who spoke of feelings of powerlessness, coercion, a lack of say in their own care and a "struggle for power" (p.1306) between themselves and staff. Another illustration is provided by Morgan (1998, p.184), whose work on user involvement in three London boroughs revealed a number of worrying findings:

"Where they did come into contact with staff, especially in hospital, the experience too often described [by users] was of being treated with disrespect and in a patronising manner... A worrying feature... was the extent of the feelings of powerlessness and fear that emerged. The anxieties expressed, and the need for reassurance that speaking up would not put them personally at risk, was too common to be put down merely to individual paranoia. People who have experienced compulsory admission to hospital, ECT and having to take medication that they have neither chosen nor understand, know what it is like to be

Figure 7 Users' Experiences of Compulsion under the Mental Health Act 1983

In Barnes et al (2000, pp.12-13), 11 service users of compulsion under the Mental Health Act emphasised the potentially disempowering nature of service provision:

- People experienced hospital in terms of "containment" with little concern for people's distress and need for understanding: "I thought I was in some sort of prison."
- Relationships between users and staff were generally antagonistic: "In hospital it was very much 'them and us'."
- Detention led to feelings of powerlessness: "It was scary. I had absolutely no control."
- Physical restraint and special observation could be "degrading" and "humiliating."
- Medical treatment was enforced without dialogue or discussion: "You can't negotiate what medication you take, you're just given it and under section you are forced to take it."
- Services tend to infantilise users: "You lose all of your power and it's handed over to somebody else who doesn't always act in the best way. We were treated like five-year-olds instead of adults who are going through a very bad time and who need support to get better."
- Dissent could be seen by staff as being a "nuisance" or "naughty."

Overall, the researchers concluded that "it was as if the imposition of compulsory powers removed any obligation on professionals to listen to people's concerns, or consult on matters of crucial personal importance."

subject to the power of the system and of another person... The way that some of those in authority had managed this, and the legacy of fear this had left, was disturbing to us."

- User groups seeking to campaign for more responsive services often face a range of practical difficulties, such as financial insecurity and a lack of training (Cohen, 1998; Rose, 2001).
- Some workers may find it difficult to view service users as experts and resist moves towards greater user involvement. This may happen in a number of ways (see figure 8).

Methods of overcoming barriers:

In seeking to overcome these barriers, the Cases for Change literature identifies a number of possible ways forward:

1. The approach and value base of individual practitioners is crucial in seeking to bring about positive change. As McDougall (1997, p.4) observes, "empowerment is not an intervention or strategy. Rather it is a fundamental way of thinking." Thus, for service users in a study by Breeze and Repper (1998, p.1306), individual attributes were a

crucial feature of empowerment:

"All the informants [in our study] were able to identify 'good' relationships that had developed with 'helpful' nurses. A good nurse-patient relationship included the nurse: treating the patient with respect, essentially as a person, but, more than that, as a valued person (for example, exuding warmth, displaying empathy and holding 'normal' conversations with the patients); enabling the patient to have some meaningful control over their own care, for example, working with the patients to develop an appropriate and realistic care plan directed towards achieving the patient's own goals; and listening to and, especially, believing the patient. These characteristics can be considered as components of empowerment."

Similar issues are raised by Barker et al (2000, p.8), who suggest that genuine involvement and empowerment depend upon:

- Treating people as equals, with practitioner and user each bringing important qualities and knowledge to the relationship.

- Recognising the user as an expert on his/her life, its problems and potential resolutions.
 - Recognising that the user can make personally appropriate choices: he/she knows what is 'good' or 'right' for them.
 - Recognising that the user has solved life problems in the past and retains this problem-solving capacity.
 - Recognising that the user has responsibility for beginning (determining and negotiating problem identification), controlling (determining and negotiating goals and solutions) and ending the therapeutic contact.
 - Respecting the user's autonomy and personal, familial, social or cultural boundaries that otherwise define them.
2. In addition to individual characteristics, services need to be based on an explicit commitment to genuine partnerships between users and professionals and to the development of shared objectives. Thus, three-way workshops between professionals, users and carers in Bhui et al's (1998) study of London

rehabilitation services enabled each group to learn from others, while Crawford (2001) emphasises a number of issues where users and professionals may have a common purpose (such as taking action to prevent staff shortages and outdated facilities). As the National Schizophrenia Fellowship (now Rethink) (1997, p.10) observes:

"Everyone involved in the delivery of care, including service users and carers, should be treated as equal partners. Occasionally, some professionals may initially feel threatened by the involvement of service users and carers and if this is the case, then it is important that this issue is addressed so that all of the parties involved can work well together. It is essential to remember that every care partner brings something different, but equally valuable, to the relationship and that successful delivery of care depends on effective collaboration between the care partners."

3. In order to make a real difference, users need to be routinely involved in areas that have hitherto been the province of mental health and other professionals alone (see figure 9). Examples include:
- Education and training (see, for example, Campbell, 2001; Crawford, 2001; Hutchinson, 2000; Morgan, 1998; National Schizophrenia Fellowship, 1997; Rose, 2001).
 - Commissioning and conducting research (see, for example, Barnes et al., 2000; Blazdell, 1999; Faulkner and Layzell, 2000; Rose, 2001).
 - Staff selection (see, for example, Milewa, 1997, Newnes et al., 2001).
 - Being employed as mental health workers (see, for example, Davidson and Perkins, 1997; Joseph Rowntree Foundation, 1998; Perkins et al., 1997).
4. Organisations need to overcome the practical barriers to user involvement. For Bhui et al (1998, p.10) this might include:

Figure 8 Resistance to User Involvement

Some involvement may only be tokenistic (Breeze and Repper, 1998), paying lipservice to the concept but failing to engage in meaningful involvement. This can result in a situation where users are repeatedly asked to give their views but seldom see any practical difference. This in turn can lead to "consultation burnout" (Morgan, 1998, p.183) and make users less likely to involve themselves in the future.

In Carpenter and Sbaraini's (1997, p.26) study of user involvement and care management, some professionals found it difficult to change accepted ways of working:

"It was apparent that professionals did not always find it easy to move from a diagnosis-led approach ('He's got schizophrenia. He needs medication') or a service-led approach ('She looks a suitable candidate for Jane's group. I'll refer her.') A needs-led approach required the identification of the need or problem first and then discussion of possible solutions... From a review of CPA forms, it was also apparent that some professionals found it difficult to grasp the importance of recording the user's own views of their problems/needs – even though the form explicitly asked for these. What was recorded in many instances was obviously the professional's view (eg, 'Sheila... needs to take medication', rather than, for example, 'I want the voices to go away')."

For Crawford (2001, p.84), "the medical profession has often appeared reluctant to embrace these changes [the emphasis on user involvement], which challenge traditional beliefs of doctors that their skills should be measured by examining their impact of their treatment on symptoms of ill health rather than on whether or not the patient feels they have benefited from the care they receive."

For Lindow (1999, p.166), one strategy for discrediting user voices is to suggest that "when groups of service users talk about their experiences this has the status of 'anecdotal evidence' rather than human testimony."

Milewa's (1997) interviews with 12 health and social care managers found that local user forums were seen as passive (that is, to be consultative, advisory or for public relations purposes) rather than active (decision making).

In Rose's (2001) study of service users' views of mental health services, some keyworkers did not pass on letters from the researchers to potential participants. This was sometimes because they felt they were too busy, but could also be because they were hostile to the idea of interviewing service users or did not believe that users could give valid answers.

One service user involved by the Department of Health in the Mental Health NSF found the process "disempowering and damaging" (Trivedi, 2001), citing a lack of support and a marginalisation and devaluing of users as key factors.

Newcastle and North Tyneside Community Health Councils (1998, executive summary) suggest that "sometimes users are asked to get involved as a way of delaying or preventing something from happening, or to 'rubber stamp' decisions that have already been made. Sometimes organisations or professionals say that they have consulted widely when they haven't or they involve users as a point scoring exercise which, in both cases, amounts to nothing more than tokenism."

User Involvement

Figure 9 Extending User Involvement

The National Schizophrenia Fellowship (1997) provides good practice guidance on involving users and carers in education and training, making reference to a 1994 review of mental health nursing in England. This recommended that users and carers could usefully be involved in developing the curriculum, delivering training and evaluating educational courses.

Rose's (2001) work on users' experiences of mental health services trained service users as researchers. As a result, users were responsible for developing research questions, carrying out the research and analysing the results. This was felt to produce much better results, as participants "visibly relaxed and opened up once they realised the interviewer had 'been through the system' and understood their own situation" (p.4).

Newnes et al (2001) describe an attempt to involve service users in recruiting a clinical psychologist. An evaluation suggested that some participants felt that questions from the service user were "wise and thought-provoking." In particular, the user was seen as being able to offer a human perspective that was well respected – "she came up with questions none of us professionals would ever have thought of and got a much stronger sense of what the candidate was like as a person."

Perkins et al (1997) report the findings of a project to recruit mental health service users to clinical posts in an inner London mental health service. Although there were numerous practical barriers to overcome, the project provided much needed employment for the 'user employees', recognised the specialist skills and expertise of service users and made these available to other user and staff within the service, and had a positive effect on staff attitudes and practices.

Figure 10 Beyond User Involvement?

"I have worked in user-led organisations for some years and would only view user involvement in the wider context of a range of activities, perhaps characterised as 'user action', that have been generated by service users and directed at changing our status within society as a whole. This action does include involvement to change mental health services, but is equally concerned with public education, influencing the media, creating new self-help approaches and developing our own understanding of devalued areas of personal experience. In short, many service users may be less interested in greater involvement in services than in more equal involvement in the community, in society and in life. We should remember that most people with a diagnosis of mental illness want to be seen as citizens, not service users."

(Campbell, 1997, pp.31-32)

"The great irony about service user action in the past 15 years is that, while the position of service users within services has undoubtedly improved, the position of service users in society has deteriorated. As a result, it is at least arguable that the focus of service user involvement needs adjustment. Service users and service providers should accept that the quality of life of people with a mental illness diagnosis in society, indeed their proper inclusion as citizens, depends on education and campaigning. Although the quality of mental health services will continue to be a dominant issue for service providers, it might no longer have such a place in the agendas of service user organisations. The climate may be changing – the Disability Rights Commission, the Human Rights Act, bioethics etc. We should not expect service user involvement not to change. Up to now it has been inward-looking and about initiatives with mental health workers. In the future it could look outwards and mean partnerships with people with physical disabilities, Black and ethnic minority groups and the poor."

(Campbell, 2001, p.81)

"Mental health service users... are now paying more attention to attacking the discrimination they face and adopting the kind of rights-based approach to securing support and countering prejudices which the disabled people's movement pioneered."

(Beresford, 2000, p.22)

- Pre-meeting talking through the agenda.
- Support in meetings if distressed.
- Appropriate pace of meetings.
- Providing administrative and secretarial support.
- Choosing an appropriate environment. A more detailed checklist is provided by the National Schizophrenia Fellowship (1997, pp.4-5; see also Further

Information at the end of this booklet), who raise additional issues such as covering out-of-pocket expenses, considering whether to pay users a fee for their involvement, ensuring adequate preparation, avoiding the use of jargon and the role of the chair in enabling everyone to make a contribution.

5. Workers should focus on the strengths and abilities of service users rather than on their perceived weaknesses or problems (Rose, 2001). As McDougall explains (1997, p.4):

"Empowerment should be solution-focused, forward-thinking and should emphasise patients' inner strengths and resources. This is in stark contrast with the culture of mental health nursing, which is predominantly problem-focused."

6. User-led services offer the opportunity to develop alternative approaches to those offered by traditional mental health services (see, for example, Beresford, 2000; Forbes and Sashidharan, 1997; Lindow, 1999).
7. To date, attempts to empower and involve service users have tended to concentrate on existing mental health services. For some commentators, however, (see, for example, Beresford, 2000; Campbell, 1997, 2001), this is too narrow a concept of involvement and we need to broaden our focus to include a wider range of issues (see

figure 10). Possible examples for such a broader concept of user involvement could include:

- Educating the public to reduce stigma and discrimination.
- Promoting social inclusion.
- Campaigning for rights-based legislation for people with mental health problems (similar to statues such as the Race Relations Act, the Disability Discrimination Act or the Human Rights Act).
- Moving beyond mental health to consider the similarities which people with mental health problems may have with other groups such as those in poverty, people with physical impairments and people from minority ethnic communities (see the booklet on Anti-discriminatory Practice for a discussion of the way in which many groups of people have a common experience of discrimination).

Above all, however, it is clear that user involvement cannot be a one-off intervention or a discrete programme of work, but a much broader and more empowering way of working which affects every aspect of mental health provision. As Hutchinson (2000, p.26) explains:

"If users are to regain some control over their lives there needs to be a shift in the balance of power between themselves and

mental health professionals... The key element to achieving this shift is to involve service users at all levels of the mental health system: in the planning of their own support; in the design and running of statutory and independent services; in the recruitment of staff; in the training of mental health professionals; in monitoring the effectiveness of services; in researching and evaluating services, and finally, in the establishment of user-run or user-led services."

Only when users are routinely involved at every level of the mental health system will genuine partnerships between users and mental health practitioners be possible.

Further Information

- A number of user-focused studies shed light on users' experiences of mental health studies and their priorities for change (see, for example, Mental Health Foundation, 1997; Rose, 2001; Rose et al., 1997). In particular, the Mental Health Foundation's Strategies for Living programme seeks to emphasise that we are all experts in our own mental health and to explore the ways in which people live and cope with mental health problems (Faulkner and Layzell, 2000). Further information on the project is available via the Mental Health

Foundation's website (www.mentalhealth.org.uk).

- The National Schizophrenia Fellowship (1997) publishes a practical guide to involving users in areas such as their own care, service planning, education and research.
- The Our Voice in the Future project is designed to give people who use services and receive welfare benefits a say in the future. As part of this process, Beresford (2000) has published a booklet on mental health issues which provides a useful summary of many of the issues discussed above.
- Barnes and Bowl's (2001) Taking Over the Asylum provides one of the most comprehensive and up-to-date overviews of empowerment and user involvement in mental health, and is a useful starting point for anyone wishing to understand the issues explored in this booklet in more detail.

Critical Commentary

I think the point that there was a change in the 80's away from institutional care is valid, but one of the other motivators apart from consumerism and choice was the cash releasing effect for government. It was keen to sell off surplus land and this was a prime mover in the growth of more community-based services. Also, the fact that one could get lower unit costs for care in the smaller community units and independent living. The "acid test" was and still is am I getting the best care and medication for my condition? The answer is no. You are getting the most economical. Thus there are too few psychiatrists and too much cheap and inferior medication. Also, for the acutely ill there are still too few alternatives to being admitted and sedated.

Much perceived user involvement is cosmetic or tokenism. In my own experience, one large so-called user group was paid by a Trust to consult with their members on service plans. The opinions expressed were of the user group staff as no consultation took place.

One can check out my comments by looking at the level of re-admissions into wards and the frequency people are re-admitted. In my experience, 10 – 12% of all activity in a large Trust is re-admissions. These individuals are re-admitted some 2 – 4 times a year. Where is the choice for this large number of individuals? Rather than rely on providers' or purchasers' statements of what consumers want (one should bear in mind the work carried out on gap analysis to see how what is said compares to what is heard and even more differs from what is then put on paper), simply find out where people with mental health problems congregate – cafes and lunch clubs are favourites - and ask the people there what they think of services. This weeds out the self-selecting few who claim the right to speak for the majority.

I guess that what I am saying confirms what I took away from the chapter. The choices available are what is promoted by health care professionals not what is perceived or experienced by users. Much user involvement is cosmetic and designed to meet government dictates, not to actually respond to users' expressed views.

Lee Hayden, service user and senior manager in a mental health trust

User Involvement

Critical Commentary

This chapter proved to be a useful 'tour', charting progress and the development of service user involvement over the past twenty years. Based on my experience in working in mental health over the past twelve years, it offers a reflection on how far we have come in working in partnership with service users, and provides some key direction about the processes/individual qualities needed and practical suggestions as to how this might be sustained. It also has the potential to be used as a benchmark against which mental health communities could measure themselves. However, as these communities mature and become more sophisticated, barriers and challenges remain. These include:

- Sustaining participation and working with the benefits system, for service users who wished to be recompensed for their input. The thrust towards the 'recovery' model, and in particular, employment and training for service users can lead to major anxieties for service users who fear loss of benefits.
- Having supported the development of service user networks and involvement, there is now a real challenge for the professionals in terms of managing expectations together. This is particularly relevant in terms of the commissioning of services, decision-making about budget allocation, coupled with the pace of change.
- Becoming a service user participant, within the Local Implementation Teams for mental health for example, can also prove a source of stress for some individuals. As within any partnership, there needs to be capacity and structure within the system to support, mentor and advise service users experiencing such stresses, and/or a potential relapse.

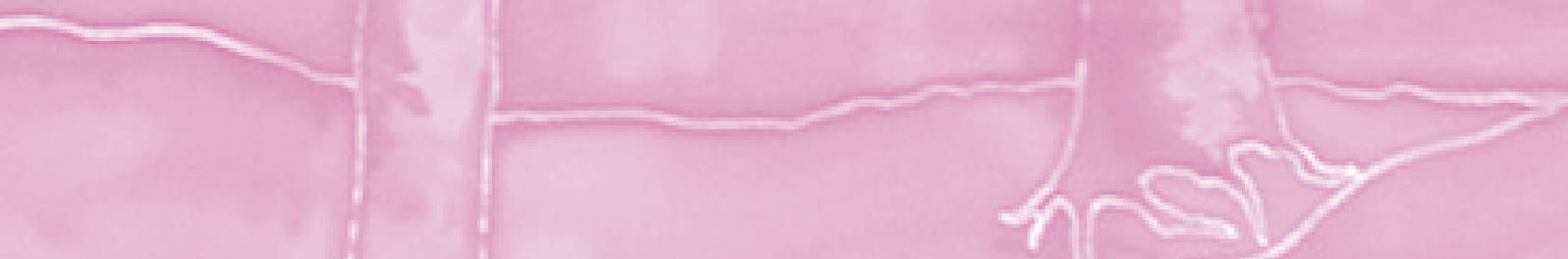
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User Involvement



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