



The results of SCMH research and analysis, presented and interpreted clearly and concisely to inform and influence policy and practice.

The Sainsbury Centre for Mental Health (SCMH) is a registered charity, working to improve the quality of life for people with severe mental health problems. It aims to influence national policy and encourage good practice in mental health services, through a coordinated programme of research, training and development. SCMH is affiliated to King's College London.

# The mental health service user movement in England

## Summary

This policy paper aims to identify and analyse organisations comprising adults who are users of mental health services across England. No systematic attempt has been made until now to find out the extent and scope of the mental health service user/survivor movement, nor how far it represents the wider constituency of service users and survivors, including those from minority ethnic groups.

A postal survey was conducted of all local mental health user groups in England. In all, 318 user groups responded to this survey and 25 were interviewed in depth. National leaders of the movement were also interviewed. Much of the research was carried out by users themselves.

## Findings

### Service user groups form an identifiable movement

The 300 local groups we identified have common beliefs and understandings that together constitute a movement rather than just a collection of separate organisations.

### Service user groups are involved in a range of functions beyond statutory consultation

Local service user groups play a very important role in mutual support, combating stigma, helping people to recover and stay out of services, and participating in local service planning and development.

### There are a number of identifiable common issues across the movement, including:

- ❖ An interest in closer links with wider disability groups on issues such as benefits and discrimination.
- ❖ Opposition to widening compulsion under the Mental Health Act.

### Women are well represented numerically within the movement

However, women, and black women in particular, do not all report positive experiences of local groups taking up their issues.

**Black people are not well represented in most service user organisations** However, some national networks are making concerted efforts to reach out to black and minority ethnic service users.

**There is no national forum to bring together the service user networks** In the 1990s, user groups did work together nationally to influence government policy; however since that time there have been fewer instances of cooperation at this level.

**Most groups are small in number, recently formed and exist on limited and insecure resources**

- ❖ Most groups have fewer than 50 members each.
- ❖ 42% of groups have been set up as recently five years ago.
- ❖ Three-quarters of groups receive some external funding, in most cases between £20,000 and £40,000 annually, for which they have to apply each year.
- ❖ 55% of groups have a paid worker.
- ❖ While two-thirds of groups have a meeting place, fewer than half have any office space.

## Recommendations

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For the service user movement to address the challenges of expressing diverse views to effect change in mental health services, investment in extra capacity will be essential.

1. **Statutory services need to invest in local user groups** and support them in improving their infrastructure in order to implement the objectives of Section 11 of the Health and Social Care Act 2001. Funding should be secure and should be given with minimum strings attached.
2. **The service user movement needs to be more strongly developed at a national level**, where user involvement currently appears to be working less well. A single national network would help to facilitate this development. There is a great deal of expertise within the movement to make such a network effective.
3. **Service users from minority communities need a bigger voice.** Some African, Caribbean and Asian mental health service users would like to organise separately as well as having a role in the existing service user movement. Service users from minority communities need finance, information and practical help to increase their ability to form networks and to develop a national voice.
4. **National good practice guidelines should be developed for service user involvement.** A task group of service users, professionals, managers and others should be set up to develop guidelines for good practice in user involvement.

## Introduction

The mental health service user movement in England is expanding and taking on new roles. It exerts growing influence in mental health service development. Yet it consists of a relatively small and poorly resourced set of organisations and individuals facing major challenges in meeting their various aims and objectives.

This policy paper describes the movement as it exists today and examines the issues it faces. Before reporting on the main findings of the research, this chapter details the background to the user movement and the context in which it works.

### Defining the movement

The mental health service user/survivor movement is referred to in this policy paper as 'the movement'.

The term 'service user/survivor movement' refers to the work of individuals who advocate for their personal and collective rights within the context of discrimination faced as a result of having experienced mental health difficulties and/or being diagnosed as having a mental illness.

The terms used by group members and individuals to describe themselves varies. They may describe themselves as 'survivors' of the mental health system, 'service users', 'clients' or 'ex-patients'. The terms used directly reflect the personal experiences of those choosing the words. For example, the choice to describe oneself as a 'survivor' often denotes a negative experience of the psychiatric system, where recovery is perceived to be in spite of, rather than due to, the intervention of mental health services.

The term 'movement' implies a broad consensus amongst individuals, groups and organisations regarding broader inclusion and self-determination.

### The origins of the movement

Patients in psychiatric hospitals came together to speak out as early as the 1620s, with the 'Petition of the Poor Distracted Folk of Bedlam'. The forerunner of modern day advocacy groups, however, was the Alleged Lunatics' Friend Society, set up by John Perceval in 1845. The Society's aim was "the protection of the British Subject from unjust confinement on the grounds of mental derangement and the redress of persons so

confined". Perceval also wrote *A Narrative of the Treatment Experienced by a Gentleman During a State of Mental Derangement* (1838), an account of his experiences as a patient in Brislington House and Ticehurst.

In the twentieth century, groups critical of psychiatry began to form in the 1970s. Some of these were alliances between patients and professionals. Groups were formed in response to a range of issues, such as improving conditions on psychiatric wards, the closure of large long stay psychiatric hospitals and giving service users a greater say in choices affecting their quality of life. Patient-only groups formed at this time included the Mental Patients Union and COPE, which eventually became Campaign Against Psychiatric Oppression (CAPO). Charities such as Mind and the National Schizophrenia Fellowship (now called Rethink) were also in existence at this time; they were, and continue to be, broad alliances of a wide range of interest groups, and are not run by service users themselves.

The mid-to-early 1980s saw the formation of local user forums for mutual support and user involvement work. Early forums were set up in various locations nation-wide. Within London, for example, groups were formed in the boroughs of Hackney, Islington and Camden. Many of these groups were for carers as well as users.

In 1985, the Mind/World Federation for Mental Health Conference was held. Dutch and US patient groups met UK user/survivor groups for the first time. This stimulated the growth of the movement, in particular, service user-led advocacy.

By the mid-to-late 1980s, the movement began to use the media more effectively. The first TV programme made in 1983 by service users/survivors, called 'We're Not Mad, We're Angry', was a critique of the psychiatric system and described personal experiences of treatment. It was broadcast on Channel 4 during a mental health season.

A notable influence on the movement was the publication in 1988 of *On Our Own* by Judi Chamberlin. This book explored the rise of the survivor movement in the US and talked about the importance of consciousness-raising and mutual support. Following this, there were an increasing number of local publications and newsletters by user groups critically examining services and describing personal experiences [JW4].

Since the 1980s, black people have also begun to give their perspective on why they are proportionately over-represented and too often failed by the psychiatric system. A wide range of voluntary and community organisations have been

established in every major British city: from the Leeds Black Mental Health Resource Centre, to Awetu in Cardiff, Black Orchid in Bristol, Frantz Fanon Centre in Birmingham and the Isis and Simba projects in South London. These groups have challenged the way mental health care is delivered to black people in the UK. They have also given voice to the concerns of users and carers. However, the survey showed that only a small number of these groups are run by service users.

Four significant user networks were formed in the mid-1980s to provide support, to share information, campaign for change and challenge discrimination. They were:

- ❖ **UK Advocacy Network (UKAN):** A national network for service user-led advocacy projects and local user forums. It provides information and support for groups and develops national policy on advocacy. It currently includes over 300 groups.
- ❖ **Survivor's Speak Out (SOS):** Initially for mental health users and professional allies in the UK, although eventually the role of allies was reduced. Its peak membership was over 900 in the 1990s, but it has now become a much smaller organisation.
- ❖ **National Voices Network (NVN):** Set up within Rethink (then the National Schizophrenia Fellowship). It currently has over 500 members.
- ❖ **The Hearing Voices Network:** Formed in Manchester in 1988, the network offers a positive framework for developing ways of coping with hearing voices and seeks to raise awareness. The network now incorporates 150 groups across the country.

### The policy context

During the lifetime of the movement, the concept of user involvement in health services has been brought from the margins to the mainstream of government policy. It is now beginning to become a part of routine practice in health and social care, in terms both of individuals contributing to their own care plans and of service users collectively getting involved in planning and monitoring services. At the same time, however, there have been developments that threaten the autonomy of people with mental health problems.

The following government policy initiatives have been of particular significance to the user/survivor movement:

- ❖ **The NHS and Community Care Act 1990.** This was the first piece of UK legislation to establish a requirement for user involvement in service planning, marking an important shift in government thinking on the role of users.
- ❖ **Modernising Mental Health Services (1999), the National Service Framework for Mental Health (NSF) 1999 and the NHS Plan 2000.** These documents set the framework for mental health service delivery over the following decade. All three place a strong emphasis on the role of users as key stakeholders in service provision and the need to transform services in direct response to users' needs. The NSF is particularly strong in addressing the potential conflicts of interest between the users and their carers.
- ❖ **Section 11 of the new Health and Social Care Act 2011.** This places a duty on NHS trusts, primary care trusts (PCTs) and strategic health authorities to make arrangements to involve and consult patients and the public in service planning, operation and in the development of proposals for changes. For more details, go to: [www.doh.gov.uk/involvingpatients](http://www.doh.gov.uk/involvingpatients)

**The Draft Mental Health Bill, 2012.** This outlines the Government's plans to reform mental health law. It is believed that the proposals, if enacted, will increase the use of compulsory treatment and detention of those with mental illnesses. Opposition to the proposals has become a major focal point, and source of controversy, for the movement, and has brought it closer to other groups also opposed to the proposals, such as charities and professional bodies.

### Current issues for the movement

The service user movement today, then, faces a wide range of issues. Service users are not simply concerned with psychiatric care, but with the whole of their lives. Their concerns include tackling the stigma of mental illness, access to benefits and employment, and opportunities for social inclusion and recovery.

However, statutory user involvement and consultation in mental health services are making big demands on the time of local groups. This has raised issues about the independence of the movement as well as its capacity to meet increases in demand for this work. It is against this background that our study was carried out.

### Study purpose and methods

No systematic attempt has been made until now to find out the extent and scope of the mental health service user/survivor movement, nor how far it represents the wider constituency of service users and survivors, including those from minority ethnic groups. SCMH decided to carry out such a study, which would also look at the role of user involvement in the reshaping of mental health services. The focus for this study was exclusively England because of the differences in mental health legislation and methods of involvement in other parts of the United Kingdom.

The study began in 2001 with the following aims and objectives:

1. To describe and analyse the mental health service user/survivor movement in England (in particular to find out about the extent to which Black service users are part of this or are organising separately).
2. To describe and analyse the extent and effectiveness user involvement in England.
3. To make policy recommendations to build on and improve the current situation.

In order to discover more about the survivor/user movement, a postal survey was conducted of all local mental health user groups in England in the first half of 2001. In all, 318 service user/survivor groups responded to this survey. Based on the responses to this, a more in-depth piece of qualitative research was carried out by contacting 25 of these groups selected from across all the regions of England, to set up visits and interviews, as well as talking to 30 national figures in the movement.

The survey questionnaire and the in-depth research tools were created following consultation with and final approval of the project Steering Group, all whose members were service users. The questionnaire was designed to be short and simple (just two A4 sides) to encourage maximum returns. Many topics were covered with scope for both numeric and qualitative information to be fed back.

## Findings

This section summarises the findings of the project by describing:

- ❖ the main messages to emerge from the research;
- ❖ organisational characteristics of the movement;
- ❖ the main activities of the service user/survivor movement;
- ❖ service user group contributions in making change on a local and national basis;
- ❖ the movement's response to diversity;
- ❖ the main tensions within the movement;
- ❖ descriptions of selected major national user organisations

### The main messages to come out of the research

#### 1. The existence of a movement

This project began with the brief to determine if it could be said that a movement existed. The dictionary definition of a 'movement' in this context is:

- a. a group of people with a common ideology.
  - b. the organised action of such a group.”
- (Collins English Dictionary)

After conducting a postal survey of 318 groups, the conclusion of this research is that these groups do indeed form a movement: they do not merely exist in isolation from one another, and their members do have common beliefs and understandings. The movement developed rapidly in the 1980s and 1990s, partly because of community care policies – which gave service users more freedom to organise – and partly because of the work of dedicated individuals. It could however be said that there is at present a lack of cohesiveness in the movement as it does not have a strong national profile or sense of unity. While there are a number of national networks and organisations, there is no forum where these networks can come together regularly to discuss shared issues.

#### 2. The functions of the movement

Local service user groups play a very important role in mutual support, combating stigma, helping people to recover and stay out of services, and participating in local service

planning and development. However, much of their effort is voluntary and unpaid and most groups exist on a shoestring budget often relying on year to year funding from money left over in statutory health and social service budgets that needs spending before the end of the financial year.

### 3. The representation of women

Women are reasonably well represented numerically at least in the movement though this can vary among local groups. However, women, and black women in particular, do not all report positive experiences of local groups taking up their issues.

The Government has recently acknowledged the specific needs of women who are service users with its strategic report, *Women's Mental Health: Into the mainstream* (DoH, xxxx). Yet there is no specific mention in the report of developing the capacity of national and local service user groups in terms of improving services for women. Direct input by women users will be essential to bring about real improvements.

### 4. The representation of black and minority ethnic groups

Minority ethnic groups are not well represented in most user organisations, though some national networks are making a concerted effort to reach out to black and minority ethnic service users. Many of the black people who were interviewed in the research called for the small number of specifically black and minority ethnic user groups to be supported to create national networks and get their voices heard more directly.

### 5. Common interests

There are identifiable common issues in the service user/survivor movement. There is agreement regarding the need for mental health organisations actively to integrate user views into policy and service delivery. There is a broad consensus that statutory bodies and professional mental health workers should listen more to service users' views and offer more respect, choice, information and alternatives. There is also interest in closer links with the disability movement on issues such as rights, benefits and combating discrimination. Most people in the movement are opposed to widening compulsion under the Mental Health Act.

### 6. Representation of non-members

Groups are frequently challenged about their ability to speak for service users who do not join them. However, there is currently no alternative means of representing the views of those service users who are not part of the movement. To be representative, user involvement depends on local groups including a broad cross-section of users.

Some user-led research, in particular that using the User Focused Monitoring methodology developed by the Sainsbury Centre for Mental Health, shows that non-members' concerns may not be so different from those of movement members (SCMH, 2001).

Better and more sustained funding would enable the movement to represent non-members better by increasing its capacity for outreach and network building.

### 7. National networks

National networks are effective in enabling voices within the movement to be heard at a national level. They also allow for differences to be debated openly. In the 1990s, when leading national service user/survivor networks (SSO, UKAN, Mindlink) came together via Mind and the Government's Mental Health Task Force, they were able to influence the national agenda to some extent. This higher profile led to the development of user-led research projects and innovations such as advance directives and self-management strategies. Currently, however, there is no national forum to bring together the leading service user networks.

## Organisational characteristics of the service user/survivor movement

The information below is derived from the postal survey of 318 local groups, which have a combined membership of around 9,000 service users/survivors, as well as from the in-depth qualitative study, whose respondents include local group officers or workers, national leaders and project workers from six national service user/survivor networks with a combined membership of 6,800 individuals and 450 local affiliated groups[JVV9].

Below are some of the key organisational characteristics:

Topic	Response
Membership based on mailing lists	Most local groups have fewer than 100 members on their mailing lists. Less than 25% of groups have more than 100 members, while 42% of groups have fewer than 50.
When groups were set up	The majority of groups (75%) have been in existence less than 10 years, and 42% of groups were set up during the past five years. Only 10% of groups have been in existence more than 15 years.
Funding	77% of groups receive external funding. This ranges from £35 to £360,000 though most groups are at the lower end of this range, receiving £20,000 or less per annum The most common source of funding is from Local Authorities (44%) followed by NHS commissioning bodies (31%), charitable trusts (31%) and finally NHS Trusts (19.5%).
Paid workers	55% of groups have a paid worker
Elected management committees	56% of groups' co-ordinating group (e.g. management committee, steering group) is elected at an AGM or similar meeting
Premises	70% of groups indicated that they do have premises, though this is often just a place to meet rather than an office

From the above findings, it can be said that a majority of user groups are recently formed and generally comprise relatively small numbers of people. More than three-quarters of these groups receive external funding, but amounts are generally not high. While two-thirds have meeting places, few have dedicated office space. More than half, however, do have a paid worker.

The above findings suggest areas in which local groups could be strengthened by increased and more reliable funding from commissioners or other organisations. In particular, they would benefit from having the option of recruiting paid staff and of finding business and meeting premises.

### The main activities of the movement

The most common activities amongst service user groups are mutual support and practical advice but there are many others besides these. This research inquired into the exact nature of movement activities. The table below summarises the findings:

Frequency of full meetings	Most groups (72%) meet at least once a month. Only 11% meet less frequently.
Group activities	79% self-help and social support 72% consulting with decision makers 69% education and training 41% creative activities 38% campaigning 36% advocacy 28% other
Average meeting attendance	Most commonly, between 5 and 14 people attend each meeting.
Group representation on committees	66% of groups indicated that they are represented on planning bodies etc
Expenses – the proportion of groups who list each of these as items in their budget.	76% communications 71% expenses 62% equipment 54% premises 48% workers [JWI0] 42% campaign materials
Group links – locally, regionally and nationally	77% have local links 52% have regional links 62% have national links

The quotations below, taken from the survey, illustrate the activities listed in the table.

### Self-help and social support

*“Self-help is tremendous for people, watching people grow up through it, coming along feeling thoroughly demoralised just out of hospital and thinking that they’re good for nothing and feeling dreadful about themselves, doing a bit of voluntary work with us, gradually taking on responsibility, and then ending up going off benefits and working for us, and managing things and getting really involved.”*

### User involvement/consultation

*“We’re well known in the user community and certainly the statutory agencies tend to treat us with quite a high level of respect, particularly because we’ve been able to do events that they’ve been very grateful to be present at. I think we’ve pushed forward the user involvement process a lot faster than it would have happened otherwise.”*

### Education and training

*“We are going to be doing some work around relapse prevention, not a term I particularly like, a piece of jargon. It’s a model from the States, it’s much more social model and treating people as individuals. People have their own plan that they go through training to develop, so it’s very much around self-management and taking responsibility yourself for your own signs of distress and what you do about them. The person is at the centre of it, but it includes services as well as individual things and people’s own strategies as well. They will go on to train professionals in using it so it moves up from there.”*

### Creative activities

*“Our key aim is to use our creativeness and our skills and talents and to revive our sense of hope and to smile and laugh if possible, because we’d seen User groups become so involved in campaigning that they lost their support function.”*

### Campaigning

*“We do a lot of campaigning, to stop black people being 80% of the system. There is a lot of black kids with identity problems, especially mixed race, shared heritage, and it’s not being addressed.”*

### Advocacy

*“If service users want us to be their voice we will, but if they want us just to sit there in the ward round, and give them more courage, we’ll do that. I think the best thing, when we’ve been a success, is when someone says ‘well actually I don’t need your advocacy any more, I can do it myself.’”*

## User group contributions in making change on a local and national basis

User involvement is clearly occurring locally, with 72 per cent of groups represented on local planning forums. But this may not be leading to great changes in service provision. Observers at LITs were surprised to find the low priority given to service user-led projects. There seemed to be little flexibility for the priorities of user representatives, such as advocacy projects or ethnic minority user groups, to be considered. Little money seemed to be available for the voluntary sector or for expanding and improving local services.

In many of the meetings the main role for service user representatives was to help decide what was to be cut. Real commitment to change based on users’ views, as well as increased efforts to strengthen local and national user infrastructures, would help to take the process forward.

The Mental Health Task Force set up by the previous government had the task of investigating the implementation of community care policies. As part of this work a Task Force User Group was set up, drawn from UKAN, SSO and Mindlink. This group carried out a wide consultation exercise among service user groups around the country to find out their views on mental health services. It also developed a training pack for service user trainers, a guide to advocacy and a set of guidelines for negotiating local Charters for mental health service users. This work did advance the movement’s sense of national unity, though it is not clear how far any real changes resulted from it.

More recently, the National Institute for Mental Health England (NIMHE) has set up a User and Carer Expert Committee and a number of regional user champions have been appointed. There was no process of formal consultation on this structure of involvement with the national organisations of service users. However, there is the potential for this structure to evolve into something more representative of the service user/survivor movement in the future, perhaps via the Regional Development Centres, many of which are now appointing user development workers.

### The movement's response to diversity

Some of the most effective movements, such as the disability movement, the feminist movement and the US Civil Rights movement, have involved people with a diversity of views coming together for specific purposes. Accordingly, one of the most important things the movement has agreed upon is the right for individuals to have different needs.

Many black and minority ethnic service users are finding that the movement is not addressing their specific issues. This is leading them to want to organise separately, perhaps relating more to other black community organisations than to the service user movement. Black service users/survivor groups could take on a valuable role providing mutual support and information from within their communities as well as acting as a 'gateway' to statutory services.

Issues around sexuality are currently not well understood in the movement, and more work needs to be done to raise awareness. Most group officers in our survey felt that there was a lack of awareness in the movement on issues of sexuality and thought this was an area their group could and should do more about. The importance of gay representation is illustrated by the experience of a group co-ordinator, who is gay, who stated that issues around sexuality are talked about a lot more since he became involved in his service user group.

### The main tensions within the movement

Like any movement, the mental health service user movement has its tensions and differences of opinion. Most of these centre around the degree to which the movement should accept existing systems and practices: essentially, whether it should seek reform or revolutionary changes. The following five controversies are all dimensions of that dilemma.

#### ❖ **Forced treatment and detention**

Forced treatment and detention are arguably two separate issues requiring individual attention. The existence of compulsion is seen by some as preventing services from ever being truly user-centred. If truly responsive services were available, they argue, there would be no need for compulsion.

A small number view compulsion as sometimes necessary because they themselves have felt they needed it at times. Some make a distinction between compulsory detention in a place of safety and compulsory treatment, regarding the former, but not the latter, as justifiable to save lives.

#### ❖ **Biomedical model of mental health**

The biomedical model of mental health is seen by some respondents as an underlying cause of oppressive and inhumane services. It can at times appear that the movement is divided between those who seek to reform services and those who want to challenge the fundamental 'scientific' basis for them.

However, the movement remains united on the importance of putting the views of service users centre stage, and seeking practical solutions that enable choice, such as Direct Payments and advance directives.

#### ❖ **Establishing a rights-based movement**

The majority of survey respondents want a closer relationship with the Disabled People's Movement, as there are perceived to be many common issues. Only one respondent in seven was opposed to such links being strengthened. There is a need for more debate within the movement on the social model of disability and how this relates to mental health. Closer working would help to establish more of a rights-based movement. However, some respondents expressed concern that too close a link would compromise independence. They wanted to ensure that the mental health service user movement retains its own identity.

#### ❖ **Funding from drug companies**

The issue of pharmaceutical company funding for service user groups has caused considerable division within the movement. While almost half of respondents were clearly opposed to this, a similar proportion believe it depends on the circumstances, while a small minority are in favour. Those who oppose it do so because they believe taking money from drug companies compromises independence and that drugs are damaging. Many of those who think it may be an option or who are in favour of it say that drug companies have profited from service users/survivors and that they should give something back. Others think this is an individual ethical decision and not something the movement should dictate.

#### ❖ **Independence**

A major controversy within the movement centres on claims that its independent identity has been compromised by closer working with the Government and professionals. Some respondents felt that user involvement has weakened the movement by substituting government agendas for users' agendas. Others

see this as the movement growing up and becoming involved in real change. One respondent stated:

*“I probably want most of the same things that the most radical service users want, but my approach to getting them may be totally different – sitting round a table with people, not attacking them, trying to work with them and change things from within.”*

The movement is seen to be strong locally, with many new groups forming, but to have lost the tentative national unity it was working towards a few years ago. Since the work of the Mental Health Task Force User Group in the mid-1990s, there have been few attempts to bring together the main national networks. This has resulted in the loss of the shared sense of purpose that this joint working created at that time. National groups are not currently strong enough to influence national policy nor able to keep local groups in touch with each other with a sense of all belonging to a movement.

## Conclusions

Responses to the survey of user groups have provided a number of key messages about how the user/survivor movement could be strengthened, as well as some potential obstacles to its development. These fall into the following broad areas:

- ❖ Effectiveness
- ❖ Funding
- ❖ Infrastructure
- ❖ Diversity

### Effectiveness

Most respondents were aware of the achievements of the user movement and they felt part of it. They acknowledged the effectiveness of activities such as speaking out for oneself or for other users, mutual support, campaigning for rights, and working together for better services. They also recognised the usefulness and effectiveness of survivor-led alternatives.

User involvement has become a major work area for many user groups. It is working fairly well in many localities, with 72% of groups involved in local planning processes, and with a perception that user involvement is now accepted by professionals. It is working less well at a national level, partly because the movement is currently not well organised at this level. There is not currently much evidence to show whether or not user involvement is effective in leading to change. \* User involvement appears to be having an influence but the capacity to achieve change is limited by lack of money for new services and centrally determined agendas, which may not be flexible to local needs and wishes.

The service user movement has considerable potential beyond user involvement. It offers the potential for important and unique contributions towards mental health promotion, for example. Service users also have an important role to play in eliminating stigma and discrimination against those with mental health problems. This is one of the common functions of national and local service user groups. Their capacity and willingness to put across their messages, particularly in national government initiatives, could benefit mental health policy and service delivery. The work of Mental Health Media has been an example of empowering users in dealing with the mass media.

## Funding

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If user involvement is to make a real difference, it needs to be properly funded and resourced. The current position, however, is that user involvement often depends on the work of service user groups who are poorly funded and therefore may not have the time and resources to provide the input needed.

On a local level, there are wide variations in funding of service user groups and of user involvement, with no apparent consistency, indicating a lack of any national or regional strategy towards user involvement and capacity building.

Drug company funding is an extremely divisive issue for the movement. Some users see it as a betrayal and a sell out of the movement's principles, whereas others feel that it would be an acceptable source of funding if given without conditions.

## Infrastructure

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The research showed that many groups rely on committed but sometimes fragile individuals. Without a strong infrastructure, even national organisations may be vulnerable. Groups who tend to rely on a small number of key individuals with skills such as chairing or money management may find that the group is unsustainable if those people become overloaded or if they have to take time off.

Resource constraints have limited the movement's ability to invest in the infrastructure they need to develop effective organisations. Funders often fail to consider, for example, the need to help local groups find premises. Groups could benefit considerably from investment in IT support, enabling them to connect with one another and with individual members more effectively. Support in working with the mass media, in order to communicate with the public at large, would also be beneficial. In general, more resources are needed to build the capacity of the movement to reach out and be accountable to a wider group of service users.

## Diversity

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The mental health user movement incorporates a diverse set of people, philosophies and objectives. Yet it has not always been able to reflect its diversity in the way it functions and relates to statutory services. There has, however, been considerable progress recently, especially in responding to ethnic diversity. Mainstream user

groups have increased their efforts to reach out to black communities, and black communities themselves are beginning to form their own user groups.

A major controversy remains, however, over the extent to which the movement should seek to find common ground between its diverse parts or whether disparate groups should work separately to pursue their individual agendas. The main dividing lines within the movement concern philosophy, ethnicity, gender and sexuality.

## Philosophy

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A major challenge is the differing user and survivor views of mental illness itself. Some respondents wanted to distinguish between the service user movement and the survivor movement. The distinctions involve how users view their illnesses in relation to the biomedical model. Broadly speaking, survivors tend to be more challenging of the scientific basis of mental health services. Conversely, other users tend to see working with or within the system as the way forward. This fundamental difference informs decisions about how far the movement should be involved with mental health professionals. It also affects thinking in a range of other areas including the acceptability of different funding sources.

## Race and ethnicity

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Many of the black service users who responded to our survey stated that they did not identify themselves as belonging to the user/survivor movement. This raises the question of whether black users should organise separately instead of seeking to become part of the larger movement. There are differing views on this, but it has been noted that a number of black users have begun voting with their feet and setting up separate groups. However, some respondents also expressed the view that a black service user movement should work alongside the wider movement so that their issues do not get marginalised.

## Gender and sexuality

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Although women are well represented in the movement, and head some of the national networks, there is still plenty of work to do on raising awareness of gender issues for both women and men, and especially in raising awareness of sexuality issues. This may be for various reasons,

but at this time gay and lesbian service users are not well represented within the movement. There are no specific user-led groups for gay and lesbian service users.

### Areas for further research

This has been the first systematic attempt to gauge the state of the English mental health service user movement. It raises any question which should be the subjects of further research, including:

- ❖ Collecting evidence to determine the effectiveness of user involvement, to capture the experiences of those who participate, from which to produce guidance on effective practice, both for user groups and for statutory bodies.
- ❖ Examining how a national network for service users from diverse ethnic backgrounds can be developed.
- ❖ Investigating what helps/inhibits recovery and social inclusion (maybe small local action-research projects, or a national study of community services and self-help networks).

## Recommendations

From the findings and conclusions of this study, it is possible to put forward a set of recommendations with the aims of:

- ❖ strengthening the movement;
- ❖ enhancing its representativeness;
- ❖ improving the way statutory bodies involve users in their decision-making.

At the start of the twenty-first century, it is essential to develop more robust and reliable means of incorporating service users in all areas of mental health service planning and delivery. Through Section 11 of the Health and Social Care Act, the Government has made this a mandatory requirement as of 1st January 2003.

Specifically, Section 11 of *Health and Social Care Act* states:

#### **“Public involvement and consultation**

*(1) It is the duty of every body to which this section applies to make arrangements with a view to securing, as respects health services for which it is responsible, that persons to whom those services are being or may be provided are, directly or through representatives, involved in and consulted on*

- (a) the planning of the provision of those services,*
- (b) the development and consideration of proposals for changes in the way those services are provided, and*
- (c) decisions to be made by that body affecting the operation of those services.”*

This research has examined the breadth of people’s experiences across the country. Clearly there is no neat or prescriptive consensus about what needs to happen. Nevertheless, the findings indicate there is enough common ground on which to base an action plan. An overarching theme identified by the research is the need to build the capacity of the movement by strengthening the infrastructure of its component organisations. By empowering service users in this way, their input to statutory agendas will increase and be more representative of the majority of non-activist service users.

The five recommendations below are intended not just to build capacity, as described above, but also to help take forward a new, more holistic and user-centred way of providing mental health services.

**1. Build capacity through investment in local user groups**

Statutory services should invest in local service user groups and support them in improving their infrastructure. Funding should be secure and should be given with minimal strings attached, with conditions rightly set about good financial practices but not about controlling what service user groups can say and do.

Expertise in kind could also be provided, for example by encouraging the development of wider user networks by providing improved IT equipment and support, and offering other kinds of practical help such as meeting places and, crucially, office facilities.

Beyond the local level, the Regional Development Centres (RDCs) of the National Institute for Mental Health in England (NIMHE) could play a key role in supporting the development of service user/survivor-led services, self-help and information networks.

■ Lead organisations: PCTs, mental health trusts, social services departments, RDCs.

**2. Create a national network**

The user movement needs to be strongly developed at a national level, where user involvement currently appears to be working less well. Capacity building, based on existing national and local service user/survivor organisations, will be required. The research identified the key stakeholders in this area, including UKAN, Mindlink, Hearing Voices Network, Voices Forum, and local user groups. The expertise of these groups gained from experience of mental health services and from working with service users offers a significant knowledge resource. This resource could prove to be vital in strengthening the movement nationally.

These groups should work together to create a national network of user organisations, whose functions might include:

- ❖ The creation of a single national movement website and online journal.
- ❖ Co-ordinating mental health promotion activities of user groups through training, networking and publishing.
- ❖ Supporting user and survivor-led research projects to improve understanding of their perspectives on key issues.

The culture of cooperation that has been engendered by the Mental Health Alliance forms a strong starting point for the development of a network of this kind.

■ Lead organisations: NIMHE, Sainsbury Centre for Mental Health, Mental Health Foundation, Mind and Rethink.

**3. Develop a stronger voice for minority groups.**

A growing movement of black and minority ethnic service users is struggling for resources and recognition. It is clear that some black African and Caribbean and Asian mental health service users would like to organise separately as well as having a role in the existing service user movement. They need the resources of finance, information and practical help to increase their ability to form networks and develop a national voice.

The Sainsbury Centre for Mental Health publication, *Breaking the Circles of Fear* (SCMH, 2002), recommended that the Government should utilise funding opportunities such as Section 64 and neighbourhood renewal grants to black African and Caribbean community organisations to strengthen their capacity. It argued that these groups should be supported by statutory bodies to act as ‘gateway’ agencies fostering communication between black people and mental health services.

The growing number of black user groups and gateway agencies will need a network of their own. This should ensure that their local work is represented nationally, and facilitate communication of ideas and best practice,

■ Lead organisation: NIMHE

**4. National good practice guidelines for user involvement**

A task group of users and professionals should be set up to develop guidelines for good practice in user involvement. These guidelines should be based on the following 10 criteria:

1. Making user involvement the norm.
2. Providing a base of support and accountability.
3. Examining and dealing with power imbalances.

4. Establishing outreach services that are relevant to service users/survivors.
5. Enabling service users/survivors to make their own decisions about involvement.
6. Valuing the skills of service users/survivors and helping them gain new skills and confidence.
7. Providing financial compensation for service user/survivor services.
8. Providing user involvement training for professionals.
9. Distinguishing between the needs of users and carers;
10. Ensuring the development of effective user involvement policies for NHS trusts and RDCs, together with programmes for acting on the outcomes of involvement.

The Department of Health should issue the guidelines to mental health trusts, social services and primary care trusts.

Service users have already made numerous suggestions for enhancing the National Service Framework for Mental Health, for example in the areas of preventing mental illness, promoting access to employment and self-management of mental illness. When the NSF needs to be revised, service users' perspectives should be at the centre of the process.

- Lead organisation: Department of Health

## Major user organisations

Below is a description of some of the major national user organisations. What most of these groups have in common is that they are national organisations that form a coalition of various user groups. The groups below represent a diversity of users and are often involved in user empowerment and social inclusion work as well as statutory consultation.

### National Voices Forum – 'Voices'

#### Aims

The National Voices Forum is the service user and survivor network based in London within Rethink (the organisation formerly known as the National Schizophrenia Fellowship). Voices, as the Forum is called, aims to support people who are diagnosed with schizophrenia and related conditions, through advice, social contact and encouragement. Voices is also involved in attempting to de-stigmatisate schizophrenia, particularly the myth that all people with schizophrenia are violent.

#### Structure

The Voices Forum is part of the Rethink charity and is based at their central office. However, Voices does have the right to take policy positions independently from the parent organisation. Meetings – which are for service users/survivors only – are held quarterly in Birmingham, and are open to all members, who receive travel expenses. They are the main decision making body of Voices Forum. There is an elected Chair, Vice Chair and Treasurer.

#### Funding

The Voices Forum manages its own budget, which is negotiated annually with Rethink.

#### Membership

The membership of the National Voices Forum comprises about 500 service user/survivors across the UK. The gender ratio is 2:1 men: women. Ethnicity is not currently monitored.

#### Activities

In addition to pursuing its stated aims listed above, the National Voices Forum is represented on the Rethink Board of Trustees, as well as other Rethink national committees. Voices members also are involved within the Patients & Carers Liaison Group at the Royal

College of Psychiatrists. Some members of the Voices Forum are interested in self-management. Self-management entails the various personal strategies that enable users to cope and to minimise the ways in which mental ill health limits their lives. The Forum has organised conferences about every 18 months around themes of recovery and self-management. One was held jointly with Hearing Voices Network in 2000, another with UKAN in 2002.

Voices Forum website: <http://www.voicesforum.org.uk/>

## UK Advocacy Network – UKAN

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### Aims

UKAN is a registered charity and a limited company, and has rented premises in Sheffield. It aims to promote user-led advocacy groups, strengthen user involvement and provide education and training.

### Structure

Individual management committee members run the organisation during the year between annual meetings. A manager and four part-time workers form the staff. Major decisions about the organisation are made at the annual meeting.

### Funding

Funding comes primarily from the Department of Health Section 64 grant of the Health Services and Public Health Act 1968. This grant gives the Secretary of State for Health power to make grants to voluntary organisations in England, whose activities support the Department of Health's policy objectives relating to health and personal social services. The grants are discretionary and are subject to terms and conditions agreed by Ministers and approved by HM Treasury. The remaining funding is from the Voluntary Sector Trust.

### Membership

Over 270 groups are currently affiliated to UKAN, including advocacy groups, patients' councils and user forums. The advocacy groups are run by a mixture of service users/survivors and professionals. Only user-led groups have a vote.

UKAN's membership is becoming increasingly diverse, with about 50% women members and significant numbers of black and gay members. UKAN has actively worked to increase its diversity, one example being its provision of anti-racist training for the management committee and its policy of making contact with black groups and including them in outreach, training and publications.

### Activities

UKAN is involved in providing support and information to the groups, producing a newsletter, carrying out surveys on members' views, for instance on ECT, compulsory treatment in the community, and the Government's plans for advocacy in the new Mental Health Act.

UKAN organises training for advocacy groups, producing a Code of Practice on Advocacy in 1994, and more recently an Advocacy Training Pack, and a book of articles on advocacy, *A Clear Voice, A Clear Vision*.

UKAN website: <http://www.zyra.org.uk/ukan.htm>  
(Unofficial, but site lists contact info.)

## Mindlink

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### Aims

Mindlink's website describes its purpose as being "a consultative body that ensures that users and survivors of mental health services have a direct say in shaping Mind's Policies and Campaigns".

### Structure

The Mindlink Advisory panel is elected by members. Mindlink provides representation on Mind's Council of Management as well as other decision-making bodies within Mind. Mindlink is comprised of two staff – a co-ordinator and an administrator as well as volunteers.

### Funding

Funding is mainly from Mind with occasional external funding for specific pieces of project work.

### Membership

Mindlink's membership was 1,700 at the time of the interview, but all members were being asked to reapply (to ensure that people are

making an active choice to belong). Estimated membership after the re-application process is likely to be nearer to 1,000. The national advisory panel is elected by the members.

Although Mindlink operates primarily within Mind, it is also part of the broader survivor movement and has contact with other survivor organisations and statutory bodies. Mindlink has links with survivors and survivor groups across Europe.

### Activities

Members come together for training events and take part in Mind's annual conference, where they have an exhibition stand. They are invited to comment on Mind policies and be involved in Mind campaigns. There is a Mindlink representative on the Royal College of Psychiatry Patients' Liaison Group and other representatives on projects such as the Strategies for Living user-led research project.

Mindlink website: <http://www.mind.org.uk/mindlink/index.asp>

### No Panic

#### Aims

No Panic is a user-led, voluntary organisation, whose aims are to help people suffering from panic attacks, phobias, obsessive-compulsive disorders and other related anxiety disorders, including tranquilliser withdrawal. No Panic also provides support to users and their families and carers.

#### Structure

The organisation, which operates from the founder's home, includes one part-time co-ordinator and 87 volunteers. Groups meet regularly throughout the country. Some link by telephone because their problems prevent them from getting to self-help groups. There are also monthly management meetings.

#### Funding

Funding is from voluntary donations and a £10 annual membership fee.

#### Membership

Membership comprises over 3,000 people with a diversity of backgrounds.

#### Activities

No Panic has been actively involved in supporting people through a variety of media,

including a help line, telephone groups, producing booklets, tapes, audios and videos. Over 100,000 free information packs have been sent out, while the help line deals with up to 25,000 calls a year.

The organisation is also represented on a variety of panels, including the procedures-formulation panel for NHS Direct and a pioneering project with the Institute of Psychiatry training volunteers to work in the new Primary Care Units. No Panic is also raising awareness by sending information to NHS organisations and professionals such as psychologists.

No Panic website: <http://www.no-panic.co.uk/>

### Mad Pride

#### Aims

Mad Pride was formed after a group got together for a Reclaim Bedlam campaign when the Maudsley Hospital held a 500th anniversary celebration. The Maudsley is on the site of Bedlam, one of the earliest mental asylums. Many users/survivors felt this was not something to celebrate. Mad Pride's formation centered around counteracting discrimination and promoting positive images of mental health. There is also a strong campaigning objective within the Mad Pride ethos, particularly around legislative issues.

#### Funding

This is unclear at the time of writing.

#### Structure

The organisation consists of a core group of about eight people, though more get involved when events are being planned.

#### Membership

There is a mailing list of about 300 people.

#### Activities

Mad Pride is overtly political and has held several, well-publicised demonstrations.

Some past Mad Pride demonstrations have included protests against:

- ❖ The Royal College of Psychiatrists' anti-stigma campaign; arguing that psychiatrists cause the stigma through diagnosing illness and emphasising medication against some users' wishes.

- ❖ Channel 4 for its use of the name 'Psychos' in a TV drama set in a psychiatric hospital.
- ❖ Plans in Barnet, north London to close two Day Centres – Broadfields in Edgware and Station Road in Hendon.

Mad Pride chose its name similarly to the Gay Pride movement, in an attempt to reclaim the term 'mad' and de-stigmatise mental illness. In the year 2000, over 2,000 people attended an all day music festival run by Mad Pride, and the Mad Pride book sold out at its first edition. The Mad Pride website, launched around the same time, hosted the UK Survivors mailing list, the first electronic network for service users/survivors.

NB: Mad Pride is currently mourning the suicide in December 2002 of one of its leading members, Pete Shaughnessy, a popular and controversial figure who inspired many of its demonstrations and initiatives.

Mad Pride website: <http://www.ctono.freemove.co.uk/>

## Hearing Voices Network

### Aims

The Hearing Voices Network provides information and support for people who hear voices. The first UK Hearing Voices group was formed in Manchester in 1988. It was inspired by the work of Marius Romme and Sondra Escher and the Dutch self-help group 'Foundation Resonance'.

The Network's website explains its purpose: *"Hearing voices has been regarded by psychiatry as an auditory hallucination and in many cases a symptom of schizophrenia. However not everyone who hears voices has a diagnosis of schizophrenia."*

*There are conflicting theories about why people hear voices from psychiatrists, psychologists and voice hearers. The network is open to many diverse opinions and we accept all and respect the individual explanation of the person who hears voices."*

### Funding

This is unclear at the time of writing.

### Structure

The organisation has a committee and a paid worker who is currently managed by Voluntary Action Manchester, as the organisation does not yet have charitable status, but is currently applying for it.

### Membership

The network comprises a mailing list of 1,300 people who receive a quarterly newsletter, and 150 local Hearing Voices support groups. Most members have been diagnosed schizophrenic or manic depressive, but some have had no diagnosis. There is a range of age groups amongst members, but currently membership is predominantly male and white. However, efforts are being made to increase black and minority ethnic membership. Membership fees are charged for individuals (£5) and organisations (£35).

### Activities

The Hearing Voices Network frequently works with the media to raise awareness and understanding about voice hearing, providing education and training. The organisation produces a newsletter and runs groups. People have a variety of different explanations for their voices and support is available for them to explore their own perspectives.

Hearing Voices Network website: <http://www.hearing-voices.org.uk/>

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