On Our Own Terms

Users and survivors of mental health services working together for support and change

Published on behalf of
The User Survey Steering Group

The Sainsbury Centre
for Mental Health

Jan Wallcraft
with Jim Read and Angela Sweeney

On Our Own Terms

Users and survivors of mental health services working together for support and change

Jan Wallcraft with Jim Read and Angela Sweeney

Published on behalf of the User Survey Steering Group
(Diana Rose, Andrew Hughes, Jim Read, Peter Campbell, Angela Linton-Abulu,
Hilary Hawking, Hanif Bobat, Rachel Perkins, Jacqui Sealey, Carol Jenkin,
Dominic Makuvachuma Walker, Premila Trevidi)

The Sainsbury Centre for Mental Health
134–138 Borough High Street
London
SE1 1LB
Tel: 020 7827 8300; Fax: 020 7403 9482
www.scmh.org.uk

A charitable company limited by guarantee registered in England and Wales no. 4373019

Charity registration no. 1091156

Typesetting and printing by:
York Publishing Services, 64 Hallfield Road, Layerthorpe, York YO31 7ZQ
Tel: 01904 431213; Fax: 01904 430868; Website: www.yps-publishing.co.uk

Contents

Acknowledgements

Many thanks to:

Steering Group: Hanif Bobat, Peter Campbell, Robert Dellar, Hilary Hawking, Andrew Hughes, Robert Jones, Nutan Kotecha, Angela Linton-Abulu, Carol Jenkin, Giles Martin, Rachel Perkins, Jim Read, Diana Rose, Jacqui Sealey, Mina Sassoon, Premila Trivedi, Dominic Makuvachuma Walker.

The Sainsbury Centre for Mental Health (SCMH): Matt Muijen, Richard Ford, Lesley Warner, Diana Rose, Joylette Hudson, Jennifer Findlay, Carolyn Farr, Rebecca Walwyn, Simon Denegri, Frank Keating, Julie Hadman and Nutan Kotecha and members of the Services Research team for help and support throughout.

A particularly big thank you to all the individuals who made this report possible by taking the time and trouble to help us out by being interviewed, filling in questionnaires, or setting up project visits, observations and focus groups in their area. All are busy people doing important work, often for little obvious reward. We hope this report does them justice.

The research team were:

Jan Wallcraft and Angela Sweeney (SCMH); Hilary Hawking, Robert Jones, Andrew Hughes, Carol Jenkin and Hanif Bobat (sessional interviewers and consultants on data analysis). Carolyn Farr and Jennifer Findlay provided excellent administrative support. Diana Rose originated the project, did the earlier work to set it up and remained available for guidance throughout.

Executive summary

This survey conducted in 2001–02 found that the service user/survivor movement in England provides a valuable resource for those seeking a better deal from mental health services and for those wanting to move away from services and rebuild their lives. It has supported advocacy, self-management, recovery and reintegration, and is helping to educate workers, the media and the general public, usually on a shoestring budget.

The movement needs and deserves recognition and financial support, which should be provided with as few strings as possible. It needs to remain independent in order to offer critical comment on services and to provide alternative sources of support and information, while being strong enough to have a real impact on mainstream service delivery for those with severe and long-term problems. User involvement is working fairly well in many localities, though less well nationally. There is a need for national standards on user involvement and for much stronger commitment at all levels to the implementation of the outcomes of involvement.

Key findings

- The service user/survivor movement exists and a large number of people see themselves as belonging to it. It developed rapidly in the 1980s and 1990s, partly because of community care policies and the encouragement of user involvement, and partly because of the work of dedicated individuals.
- Local and national groups and networks provide mutual support, take part in decision making and provide information, education and training, creative activities, campaigning and services.
- Funding for groups and networks is usually insecure and insufficient for their needs.
- The movement is predominantly white and needs to improve its ability to reflect the diversity of race, culture, gender and sexuality among service users/survivors.
- There is a growing Black service user/survivor movement which is struggling for resources and recognition.
- There is a broad area of agreement in the movement about the importance of being treated as an individual, not a label, a general dissatisfaction with the standards of existing mental health services, opposition to any extension of compulsory treatment, and demands for an end to discrimination and prejudice on mental health grounds, and for services oriented towards recovery, employment and social inclusion.
- There are issues that are controversial within the movement or that have not yet been debated fully enough, including forced treatment, the biomedical model versus more social models of mental health, closer working with the disabled people's movement and drug company funding.
- User involvement is happening at a local level with 72% of service user/survivor groups engaged in some form of consultative or decision-making body, often linked to implementation of the National Service Framework (NSF) for Mental Health. There seems a genuine willingness to involve service users/survivors, led by government policy directives. User involvement at a national level seems to be working less well, partly because the movement is currently not well organised nationally.
- Though user involvement is happening in many areas, the quality is variable. User involvement is an important part of what the movement does, but service user/survivor groups exist for many other reasons and some choose not to do user involvement work. The movement exists independently of its role in user involvement.

Recommendations

In order for the movement to reach out to greater numbers of service users/survivors and to have a substantial influence on mental health policy and service provision, there needs to be a strategy, based on a collaboration between the service user/survivor movement, the government, health and social services and voluntary organisations, with the following aims:

A. To build the capacity of the movement to support and represent service users/survivors.
B. To strengthen and develop user involvement nationally and locally so that it can have a real impact on service provision.
C. To develop a new integrated prevention, self-management, recovery and inclusion focus for all mental health services and related social and employment services.

A. Building the capacity of the movement

The movement provides a valuable service to people wanting to move away from services and rebuild their lives. It has supported self-management, recovery and reintegration, and is helping to train workers, inform the media and educate the general public, usually on a shoestring budget. It deserves recognition and financial support, which should be provided with as few strings as possible. The movement needs to retain its independence in order to provide advocacy and offer critical comment on services.

Recommendation 1: enabling stronger local, regional and national service user/survivor networks
The movement should be financially resourced and practically supported to build stronger local, regional and national networks.

- Funding for this should be secure and should be given with minimum strings attached.
- Many local groups need help with finding premises and employing workers, which might be done best via the voluntary sector with statutory funding.
- Special projects should be supported to develop local service user/survivor-led services, self-help and information networks via regional development centres (RDCs).
- There should be regional and national support for service user/survivor led research, via the National Institute for Mental Health in England's (NIMHE) Mental Health Research Network (MHRN), Mental Health Foundation (MHF) and SCMH.
- An information technology (IT) strategy is needed to help local groups to access and use internet communication, and to develop a national movement website and online journal. NIMHE and Mental Health Media may be helpful in this.
- There should be a funded national support organisation for service user/survivor workers. This could be linked to a general trade union such as General Municipal Boilermakers (GMB) or Transport and General (T&G).

Lead for local and regional development: NIMHE, RDCs, primary care trusts (PCTs), strategic health authorities (StHAs), local councils for voluntary service (CVS).

Lead for national development: NIMHE, SCMH, MIND, Rethink, Mental Health Foundation (MHF).

Recommendation 2: development of a national voice for the Black service user/survivor movement
This was also recommended by the recently published SCMH report *Breaking the Circles of Fear* (The Sainsbury Centre for Mental Health, 2002).

- Development funding is required to enable leading Black service users/survivors to come together regularly and to start a process of outreach and discussion with Black service users/survivors around the country.

- Based on this work, secure funding is likely to be required to develop the capacity for local groups to be set up to provide mutual support and a base for greater involvement in decision making.

Lead: NIMHE, SCMH.

Recommendation 3: increasing the user movement's capacity to represent diverse experiences

- A national programme should be developed to make available to service user/survivor groups quality training to eliminate any possible racism and homophobic attitudes, and to raise awareness of disability issues.
- This training could be co-ordinated by UK Advocacy Network (UKAN) and/or Mindlink with practical support (e.g. venues and equipment) from RDCs. Appropriate trainers and courses could be recommended by the Commission for Racial Equality (CRE), PACE (organisation for gay and lesbian mental health) and the British Council of Disabled People (BCODP), and adapted to a mental health context.

Lead: NIMHE RDCs and Experts by Experience Group, UKAN and Mindlink.

B. User involvement in improving services

National guidelines for user involvement should be developed and implemented. Service user/survivor priorities should be integrated into the NSF for Mental Health when it is next revised.

Recommendation 4: development of national good practice guidelines for user involvement

A task force should be set up to develop a set of national guidelines for user involvement, based on the Draft Principles on User Involvement in this report (p. 63). The Department of Health (DoH) should then issue guidelines to StHAs, PCTs and NHS trusts.

Lead: NIMHE Experts by Experience Group, leading service user/survivor networks.

Recommendation 5: revision of the NSF for Mental Health to include user perspectives on services

At the point when the NSF is next revised and updated, NIMHE (through its Experts by Experience Group) should co-ordinate a consultation exercise on how to integrate service user/survivor perspectives into the revised Framework.

Lead: DoH Modernisation Agency and NIMHE.

C. A new integrated prevention, self-management, recovery and inclusion focus for all mental health services and related social and employment services

Recommendation 6: a national forum to refocus mental health services towards prevention, early intervention, recovery and social inclusion

NIMHE should host a forum to discuss refocusing mental health services towards prevention, self-management, recovery and social inclusion. This could draw on the work of the existing NIMHE expert groups and link with other bodies such as the Social Exclusion Unit and other relevant government departments. This would then provide a basis for research and development to revitalise mental health services around a new value base closer to that proposed by the service user/survivor movement.

Lead: NIMHE Experts by Experience Group and the NIMHE Values Project.

1

Introduction: a brief outline of the work

For many years now, mental health service users and survivors in this country and worldwide have been speaking out for reform of services and social attitudes to mental health. Though this has been termed a 'new social movement' (Rogers and Pilgrim, 1991), no systematic attempt has been made until now to find out the extent and scope of this movement, how far it can represent the wider constituency of service users and survivors, including those from minority ethnic groups, and what it is saying about mental health services and society.

We felt it was time for such a study, which would also look at how well user involvement is working in reshaping mental health services. We chose to focus on England because there are different mental health laws and methods of involvement in the different parts of the United Kingdom, which would have made the research more costly and complex.

The research

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 state of the mental health service user/survivor involvement in England.
3. To make policy recommendations to build on and improve the current situation.

The process has been led and guided throughout by a Steering Group of service users/survivors, with particular attention to representing the views of Black service users/survivors (see Appendix 3).

The Steering Group met frequently throughout the process and commented on drafts of this report. All staff recruited to do the work, including the team of interviewers, had a background of personal experience as users/recipients of mental health services.

We started by carrying out a postal survey of service user/survivor groups, to which we received 318 responses (see Appendix 2: Methods used in the postal survey).

We then selected a sample of 25 groups to study in more depth, and also talked to national figures in the user movement. This research was based on face-to-face interviews, telephone interviews, focus groups, project visits and observation of meetings. We used a list of topics (see Appendix 6) but there was also plenty of scope for people to say whatever they wanted to in their own words.[1]

We held focus groups for local groups, with an average attendance of about six people. Three of these were with Black groups. We also ran a national focus group for Black service users/survivors and visited 17 local user-run projects.

---

[1] Direct quotes in the report have been edited where essential for clarity and conciseness.

We researched user involvement in three ways, by:

- conducting in-depth interviews with service users/survivors who were involved in producing the NSF for Mental Health;
- asking questions about user involvement in all of our one-to-one interviews and focus groups;
- observing seven locality planning meetings to see user involvement in practice.

(See Appendix 4: In-depth research methods for more information.)

We hope the report will be of interest and value to everyone with an interest in mental health, from MPs and civil servants with a role or a concern in improving mental health services, to those who work professionally in planning, commissioning, managing and delivering mental health services, to the people who receive mental health services and those who make up their networks of family and friends.

2

Defining the mental health service user/survivor movement

A number of previous writers (some of them service users/survivors and some researchers with a professional mental health background) have talked about the movement, using various different terms to describe it. As mentioned in the introduction, Rogers and Pilgrim (1991) researched and wrote about the British Mental Health Users Movement. Recently, Barnes and Bowl (2001) have described the 'mental health users' movement in the UK' and given some explanations for its development.

An overview

We created a definition of the movement (see Box 1) with the help of the project Steering Group and our respondents generally accepted this.

Box 1 – Definition of the movement

The 'service user/survivor movement' is a term used to describe the existence of numerous individuals who speak out for their own rights and those of others, and local groups and national organisations set up to provide mutual support or to promote the rights of current and former mental health service users to have a voice.

Group members and individuals may call themselves 'survivors', 'service users', 'clients', 'ex-patients' or other similar terms.

The term 'movement' implies that these individuals, groups and organisations share some common goals and are moving in a similar direction.

In order to discover more about the survivor/user movement we conducted a postal survey of all the mental health user groups in England in the first half of 2001. Based on the responses from this we then carried out more in-depth research by writing to a sample of the groups to set up visits and interviews, as well as talking to a number of national figures.

The idea of the postal survey was to create a 'snapshot picture' through asking brief questions on issues such as aims, activities, structures, funding, premises, staffing, membership, networking, user involvement and dreams and visions.

The first stage was conducted by Advocacy Really Works who put together a database of all the user groups in England, by sending a mapping and survey form to all groups on existing lists and databases of national umbrella organisations. The survey form asked groups to confirm their details and indicate whether they were user led or run. The mapping form gave a list of user groups in the area for recipients to correct and update.

Groups were then sent a copy of a questionnaire and a freepost return envelope. The majority of groups were sent mailings at three stages from February 2001 with a deadline of August 2001.

The questionnaire was created following consultation with and final approval of the project Steering Group. It was designed to be short and simple (just two A4 sides) to encourage maximum returns. Many topics were covered with scope for numeric and qualitative information.

Based on the findings of the postal survey, we have mapped the extent and scope of the movement in England in the first half of 2001. Table 1 shows some of the most important findings from the postal survey.

Table 1 – Summary of key findings from the postal survey

Question	Response
When were groups set up?	42% of groups said that they were set up in the last five years rising to 75% in the last ten years and 89% in the last fifteen
What do groups do?	79% self-help and social support 72% consulting with decision makers 69% education and training 41% creative activities 38% campaigning 36% advocacy 28% provide a service other than advocacy
How many members do groups have on their mailing lists?	The majority of groups, 59%, have less than 100 members on their mailing list with 42% of groups having less than 50. Less than a quarter of groups had more than 100 members
How many people on average attend regular full-group meetings?	Just over half of all meetings are attended by five to fourteen people (57%) and only nine per cent of meetings are attended by 35 or more people
How often do groups hold regular full meetings?	41% of groups meet monthly, this figure rising to 72% when fortnightly and weekly are included. Few groups meet less than monthly (11%) or more than weekly (11%)
Do groups have a paid worker?	55% of groups stated that they have a paid worker
Does the benefits system cause the group problems in paying members for work done?	39% of groups stated that the benefits system causes the group problems
Are groups represented on planning bodies, committees and so on?	66% of groups indicated that they are represented on planning bodies, etc.
Are co-ordinating groups elected?	56% of groups stated that their co-ordinating group (e.g. management committee, steering group) is elected at an AGM or similar meeting
Do groups receive funding and, if so, how much?	77% of groups receive funding. This ranged from £35 to £360,000 (most between £35–£40,000)
What do groups spend their money on?	76% communications 71% expenses 62% equipment 54% premises 48% workers 42% campaign materials
Do groups have premises?	70% of groups indicated that they do have premises
Do groups have links locally, regionally and nationally?	77% have local links 52% have regional links 62% have national links

Do respondents feel part of the movement?

In this section, we have asked respondents how they view our description of the service user/survivor movement and whether they see themselves as belonging to it.

Do you agree with the definition of the movement?

Most respondents agreed with our description of the movement, but a number had comments of their own to add. These demonstrate the range of activities and approaches that characterise the movement.

Some respondents see the movement as being about a struggle for rights, comparing it to the movement for civil rights in the USA in the 1960s, the feminist movement and the disabled people's movement. They see it as a similar movement by people who see themselves as oppressed and discriminated against by society.

Others emphasise the role of the movement in changing services and empowering individuals. Many respondents spoke about the importance of mutual support, managing one's own mental health and service users/survivors running their own services and offering support to others:

> *'I think there's a growing acceptance for survivors or service users to have a role to play, and probably a very large role to play, in helping other service users to overcome or deal with their problems.'*

Some respondents gave an overview of the movement from a national perspective. They mentioned national survivor/user networks such as Survivors Speak Out, the UK Advocacy Network and Mindlink as formerly providing a basis of the movement, which offered a sizeable membership and a wide range of views. This basis was seen to be less cohesive recently, though the principle remains:

> *'The survivor movement is still about networks of people who communicate with each other in the way that suits them. They can get together at things like the Survivor Worker Conference, through the UK Survivors' email list, through meeting up, through events that happen, the MIND conference. It doesn't amount to a constitutional survivor movement but it is certainly a national movement.'*

One respondent described the way in which different opinions and streams of the movement can flow together or move separately, even if there is no formally constituted national body to represent service users/survivors:

> *'It's a bit like the Thames or the Trent isn't it, that's moving along but feeding into it there are all these different streams. So it doesn't feel that there's a concerted service user movement – a national thing where folks come together and we agree on objectives, but I think the streams are there feeding into the main river, there's a lot happening around the country, a lot of good examples of service user involvement.'*

A Black service user comments however:

> *'It's easier to describe something in words than to actually do it.'*

Do services users/survivors feel involved with the movement?

Table 2 – All participants on their sense of belonging to the movement

	Do you feel part of the mental health service user/survivor movement?		
	Yes	No	Not sure/unclear
Group members[2]	8	10	0
Group officers[3]	17	4	2
National figures[4]	23	5	1
Totals	48	19	3

As Table 2 shows, most people that we talked to did feel they are part of the movement, but, not surprisingly, group officers and national figures are much more likely to feel involved than those who are on the margins of local groups.

We asked respondents why they became involved and stayed involved with the movement. The main reasons, like the purposes of the movement itself, relate to the struggle for rights, better services and personal empowerment.

1. Wanting to change mental health services

Some respondents feel they are part of a nationwide campaign for change:

> *'I know a lot of people within the service user movement, across the country. I have a lot of friends who are involved. I guess, also, I am somebody who's always been a bit of an activist, so for me that's not an enormous leap to feel part of something, campaigning.'*

For others this desire for change is more personal and local:

> *'I feel I am part of the movement because I recently stood up for myself against psychiatric services.'*

> *'When you're a service user, you can see a lot of things that could do with improving and I felt I'd got a lot of skills with previous jobs and education where I could actually help promote a better image of service users, so that could influence how services were run. It's quite dear to my heart.'*

2. Seeking alternatives

A number of respondents became involved in search of information and support outside of mental health services:

> *'I've had mental health problems for 34 years and nowhere could I get any answers. Nobody gave me any information from the psychiatric services. Then I was at college in the mid 1980s and I saw a notice – just a piece of paper with the address of the manic depression group on it. I wrote off for help and information and it was from there that I got interested and joined local groups and put a lot of time into finding out more about the service user movement.'*

---

[2] Group members are people who are on the mailing lists of service user/survivor groups that we selected to take part in the research, but who are not particularly active members of those groups.

[3] Group officers are people who have a formal role in one of the groups that took part in the research, i.e. either being on the management committee or being a paid worker for the group.

[4] National figures are people the Steering Group recommended should be contacted for the research and were selected on the basis that they have had a key role in developing the movement either as national or regional activists or leaders of important service user/survivor organisations.

And, at least for some, the movement has helped them to rebuild their lives:

> *'It brought my confidence back, because when you are ill you can feel really, really low down. It got me motivated again and with more energy. Something you enjoy doing and you've got hope for it, you want to go all the way through.'*

3. Mutual support about shared issues

Many respondents joined user/survivor groups for mutual support. For instance, a member of a Black service user/survivor group says:

> *'Our group is a big part of the user movement, because it was set up by users, for users, so it brings users together, and survivors, it brings us all together and like it's sharing experiences and things like that.'*

A national figure says:

> *'The user movement was important to me in enabling me to meet others who had been service users. I remember one person who wore a spider's web badge indicating how hard it was to escape from the mental health system. Little did I know how true it was to be!'*

It is important to know why some respondents do not feel involved in the movement. Is this their own choice or because they feel excluded in some way? Some people described feeling resistant to categorising themselves or others:

> *'I'm not a political animal at all so, as soon as it says 'movement', I tend to walk away. It's not my nature to want to put people in boxes. I just want to be part of the population as a whole.'*

Some respondents have decided they don't qualify for, or fit into, the movement:

> *'I'm trying to organise some service user-led research and if that comes together I suppose I'll be more confident about saying I am part of the movement.'*

> *'What I see as a service user movement is quite intellectual and I feel a bit inferior to that. Also, I use services – not happily – but to keep me alive basically and really you're not meant to say that.'*

Some felt let down or mistreated by the movement:

> *'I don't feel massively a part of it because I think the service user movement can't really work at the moment because the interests are with the professionals.'*

> *'The most discrimination I found was from my fellow service users who have made me feel outcast and contributed to my own mental health difficulties.'*

We include Black people's responses in Table 2, but we have also separated out their answers to the question about involvement, in Table 3.

Table 3 – Black service users/survivors on feeling part of the movement

	Do you feel part of the mental health service user/survivor movement?		
	Yes	No	Not sure/unclear
Mailing list members	0	1	1
Group officers	0	1	2
National figures	3	1	1
Totals	3	3	4

This shows that most Black service users/survivors that we spoke to do not clearly identify themselves as belonging to the movement. As these are small numbers, information from the focus groups is included to help clarify Black people's experiences of the movement.

Some say they don't have time to go to meetings, or find user/survivor groups focused too much on an agenda set by professionals. Some have found that general user groups don't address the issues of Black service users/survivors. Some Asian service users feel that Asians may be less willing to identify themselves as users, so may need a different way of working. One speaks about the movement in relation to the Asian community:

> *'What I think in terms of Asian communities, we are still after ten years down the road at the stage where people still now do not want to admit that they have a mental health problem, and families are still not prepared to accept the fact, so hence I think there should be a different way of working for ethnic minorities or for people from Asian backgrounds.'*

A Black focus group member is keen to be involved in the movement but has not found it possible:

> *'I envisage the user movement as being mutual support and advocating their rights but we don't seem to have a voice outside of our own [specifically Black service user/survivor group] even though I've tried to get involved with other user organisations.'*

Is there a separate movement of Black service users/survivors?

Black service users/survivors were asked if they think there is a separate Black service user/survivor movement.

The general view is that a specifically Black movement is emerging but it is very fragmented. Black respondents identify a need for existing Black survivor/user groups to come together to support and sustain one another and say that this is beginning to happen:

> *'I don't think there's a national coherent thing, but there are pockets. There are a lot of people who want to do something, who want to get involved, who are survivors of the system, who have had valuable experience that other people can learn from.'*
>
> *'At the Survivor Worker conference there was a workshop for Black people. They allocated us the tiniest room possible but it was packed with people sitting on the floor, sitting on top of cupboards, and that shows that there is a movement.'*

One respondent felt the Black movement is some years behind the white movement in its development:

> *'It is evolving, it's white with Black following on, and I think the Black movement is starting but I think it needs a lot of support. It's about six years or so behind the generic user movement.'*

Summary: is there a movement and do respondents feel part of it?

- We found that most respondents did think there was a national service user/survivor movement and that they felt part of it. This may be because their ways of working and their chosen activities fit with those of the movement, such as speaking out for oneself or for other users, mutual support, campaigning for rights and working together for better services and survivor-led alternatives.

- There are four main reasons why some people we talked to did not feel part of the movement:
  1. They don't want to join an organised group or movement.
  2. They don't feel they fit into the existing movement.
  3. They may agree with the basic aims but the existing ways of working do not suit their needs (e.g. cultural inappropriateness).
  4. They find the movement disappointing or have had a difficult time with it.

  The first reason is basically about choice. The other reasons for people feeling excluded raise issues that the movement needs to address.

- Black service users/survivors generally believe that a specifically Black service user/survivor movement is beginning to develop, but they see that much work needs doing for this to become unified and strong.

3

Development of the movement

In this section, we look at how the movement began, and some of the most important ideas and developments up to the present day (see Table 4). This shows that, although mental patients in previous centuries have sometimes come together to put forward their concerns, the most rapid and widespread period of development began in the 1970s.

Table 4 – Key developments in the service user/survivor movement in England

Date	Development
1620	Petition of the Poor Distracted People in the House of Bedlam.
1845–63	The Alleged Lunatics' Friend Society set up by John Perceval (forerunner of current advocacy groups).
1970s	First anti-psychiatry groups (some are alliances between patients and professionals). Patient-only groups include Mental Patients' Union and COPE (which later became EPOC, PROMPT and eventually CAPO – Campaign Against Psychiatric Oppression).
1980s	Start of local user forums for mutual support and user involvement work.
1983–86	Forums set up in Hackney, Camden, Islington and other towns and boroughs. Often these are for users and carers.
1985	MIND/World Federation for Mental Health conference: Dutch and US patient groups meet UK service user and survivor groups for first time.
1986 onwards	Media impact is made by the emerging movement: *We're Not Mad We're Angry* first TV programme/video led by survivors – highly critical of the biomedical model of mental illness: white and Black survivors give their perspectives on mental health services. Many individuals speak out on radio, TV and in published articles.
1986–present	First national networks of service users/survivors emerge: Survivors Speak Out network formed. Initially for mental health service users/survivors and allies in UK, eventually allies' role reduced. Peak membership 950.
1986–present	National Voices Network formed within Rethink (formerly National Schizophrenia Fellowship) (network of people with diagnosis of schizophrenia) for mutual support and recovery, and to eliminate stigma and misunderstanding. Peak membership 500.
1986	First patients' councils and user-led advocacy projects set up: Early examples are Nottingham Advocacy Group and Hackney Patients' Council.
1987–present	Mindlink: service-user network within MIND – peak membership 1,200.
1987	First national gathering of mental health service users/survivors from around the UK, at Edale event – run by Survivors Speak Out.
1988	Influential publications by service users/survivors emerge: A notable influence on the movement is *On Our Own* by Judi Chamberlin – an exploration of the rise of the survivor movement in the US. Numerous local publications and newsletters by service user/survivor groups begin to emerge, critically examining services and describing personal experiences.
1988–present	The Hearing Voices network (based on the work of Professor Marius Romme in Holland) began holding national events in 1990/91 and now has 100 groups across the country.

continued

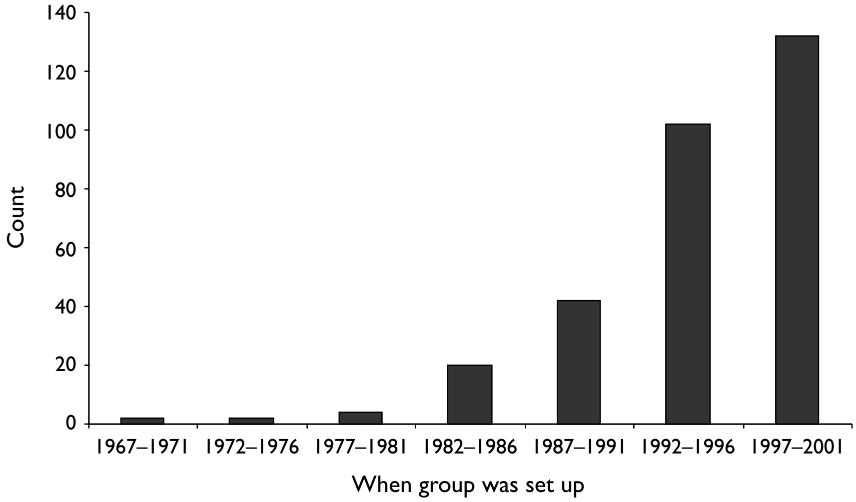
Table 4 – Key developments in the service user/survivor movement in England (continued)

Date	Development
1990	NHS and Community Care Act first establishes requirement for service user involvement in community care planning.
1991	Emergence of networks and groups for survivor art, poetry and drama: A major network is Survivors' Poetry, which runs workshops and performances, and publishes collections of survivor poetry.
1992–present	User-run services: User-run drop-ins established, including McMurphys in Sheffield and Brixton Community Sanctuary in Lambeth.
1992	UKAN (UK Advocacy Network) established. Membership of service user/survivor-led groups, focus on advocacy. Over 300 groups currently affiliated.
1992–94	Mental Health Task Force Service User Group (part of Department of Health's Mental Health Task Force) set up. Produced publications: guidelines for service user charters and advocacy, ran a series of regional service user conferences and Training the Trainers events. In 1994, National Service User Conference in Derby, attended by over 200 service users representing the movement, endorses national charter and publications.
1994–present	National Self-Harm Network set up for mutual support, information and education of mental health workers and general public on self-harm issues.
1994–present	Black service users/survivors begin setting up separate groups and organisations: These include Awaaz in Manchester, Buddies in Bradford, and Share in Maudsley Black Action (SIMBA) and Black Women and Mental Health in London.
1995–present	Service users/survivors as workers: Employment campaigns and programmes are developed by service users, including EcoWorks in Nottingham, and service user employment programme to support service users to find work within the South West London and St George's NHS Trust.
1996–present	User-led research – a number of programmes and projects are set up where research is led and carried out by service users/survivors: These include the User Focused Monitoring programme at SCMH, Strategies for Living at the Mental Health Foundation and Service User Research Enterprise (SURE) at the Institute of Psychiatry.
1997–present	Service user/survivor-led innovations for self-managing mental health problems are developed by service users/survivors: Service user/survivor-led crisis projects emerge in Devon, Brighton, Birmingham, London, Wokingham, Corby, Leeds and elsewhere. Advance directives are developed as means of ensuring choice of treatment in crisis. Manic Depression Fellowship develops self-management programme. The Strategies for Living project runs annual 'Big Alternatives' conferences, which become the focus for service user/survivor-led alternatives.
1998	PACE service user/survivor-led report on gays'/lesbians'/bisexuals' experiences of mental health services.
1999	Reclaim Bedlam campaign (protest against the celebration of Royal Bethlehem Hospital anniversary), eventually leading to formation of Mad Pride, a group that organises demonstrations and celebrations of 'mad culture'.
2001	Survivor Workers' conference in Manchester, 200 survivor workers attend. Report published 2002 (Snow, 2002).
2002	National Institute for Mental Health in England sets up service user/carer 'Experts by Experience' national consultative group.
2003	Launch of *On Our Own Terms*: report from research on English service user/survivor movement.

Is the movement growing, and if so, why?

We asked respondents if they think the movement has grown over recent years and, if so, what they think has led to this. Most do think the movement is growing. They point out a number of reasons, including social changes, political changes, individual efforts by survivors and allies, and recent collective actions to put forward survivor agendas such as self-management. The figures from the postal survey confirm that there was a rapid expansion of local groups from the 1980s onwards, with the majority set up in the last ten to fifteen years (see Figure 1).

Figure 1 – When were groups set up?



Social changes

Respondents feel that society has changed since the 1960s towards greater individual and collective empowerment. Women, Black people and young people have challenged established institutions and forced changes in old paternalistic ways of doing things:

> *'In this post-modern society people have become more demanding and assertive. Younger people aren't just going to kow-tow to their GP, like perhaps the older generation did.'*

Some respondents think there is more openness about mental health problems, so that it is now becoming easier to be 'out' as a service user:

> *'Almost every family in the country has someone who has suffered from mental health problems coming out of the closet.'*

Community care

Political changes have affected mental health services. Large asylums where patients were committed for life have been dismantled in favour of smaller local units and community services. In particular, the NHS and Community Care Act 1990, which said that service users and carers had to be involved in local planning, is seen as a factor in the growth of the movement.

The postal survey shows that 75% of groups were set up since 1992, which seems to confirm that the NHS and Community Care Act did have a strong impact on the movement. The survey also shows that 72% of local groups are engaged in consulting with decision-making bodies. The increased level of involvement of service users/survivors in speaking out and being on planning committees has a snowballing effect in that it creates role models of active service users which are likely to draw in others to the movement:

> *'I think the shift to community care is what made the service user movement possible. I used to be admitted to an admissions ward in the mid 1970s. Before that, you got sent to one of the long-stay wards and you didn't get out.'*

> *'Looking back at the 1970s, there was nothing like this. The hospitals were still treating people like animals. Now there are more opportunities. People see someone like me and think, "I could do that" and then they go and do it.'*

Payment of fees and expenses also helps to encourage people to take part. Even unhelpful government measures can stimulate the growth of the movement however:

> *'It's ironic that what most unites the service user movement are things like compulsory treatment orders, so that, when you have someone like Virginia Bottomley, that's good for the survivor movement in a strange way, because people get cross, people talk to each other and want to do something about it.'*

Dedicated individuals

Some respondents paid tribute to dedicated individuals who spoke out and gave leadership in the early days of the movement:

> *'I think the people who started up the service user movement were very angry and that gave us a lot of motivation to do something. I think that anger helped us to get through a time when we had to fight to be listened to. Then there was a critical mass reached when there were so many of us they had to listen.'*

The movement found allies among mental health workers who gave a boost to early initiatives:

> *'I want to give credit to some of the workers who have supported us. If the general manager hadn't agreed it was a good idea to have a patients' council, then it wouldn't have happened.'*

Innovations introduced by movement

The postal survey showed that 79% of groups provide mutual support, and most also offer education and training to members. Advocacy is provided by 38% of groups and other services such as drop-ins by 28% of groups. In recent years, these shared activities have helped generate new ideas such as 'self-management' of mental health problems. These ideas are becoming more widely known through the publication of books and reports. The work on self-management and the availability of user-led services is encouraging more people to become involved with the movement:

> *'One of the most important progressions which have drawn people in is the growth of self-management, like the Strategies for Living project, approaches developed by the Hearing Voices Network, the National Self-Harm Network, the Manic Depression Fellowship. When we develop our own frame of reference, this takes us away from the debate about whether services are shit or not and what do we do about them. I think that has really drawn people in because people have a chance to use their expertise and they don't need to know about the National Service Framework to do that.'*

The movement is becoming weaker and more divided

Some respondents are sceptical of service user involvement and think it has weakened the service user movement:

> *'People used to take more of a civil rights perspective than they do these days. The service user movement tends to be pretty tame and activists now nearly all work for the mental health system, so you can't expect them to lead the service user movement.'*
>
> *'I feel there isn't a user movement in the way there was in the late 80s with Survivors Speak Out. Everyone is now dispersed around different organisations so that there is user involvement (to varying degrees) but not a unitary independent voice.'*

Summary: how did the movement develop?

- Though there were early examples of mental patients speaking out, the present movement began in the 1970s with the anti-psychiatry groups. Social changes and political changes in the direction of greater individual empowerment and collective action to end oppression and discrimination have been cited as reasons for the rise of the movement.
- The movement expanded rapidly in the 1980s, with the development of user forums, national networks, patients' councils and advocacy projects. Groups and individuals began publishing newsletters, articles and critical accounts of services.
- The NHS and Community Care Act 1990 enshrined user involvement in community care planning and stimulated further growth of local user groups, but to some extent changed the emphasis of the movement from support and campaigning to local involvement.
- In the 1990s, the national networks came together to influence the Department of Health and user-led research projects were set up. User-led services such as drop-ins and crisis projects were developed and the movement gained confidence to put forward its own innovations such as advance directives and self-management strategies. An increasing number of service users/ survivors found paid employment in the mental health field.
- Government legislation and policies have made a significant difference to the movement, along with the help of allies among the voluntary sector and mental health professionals, but a crucial factor has been the commitment of individual service users and survivors, and collective action by groups.
- Questions remain as to whether the movement is becoming stronger or has lost its focus and direction, being pulled too much into the agenda of service providers.

4 Activities and support

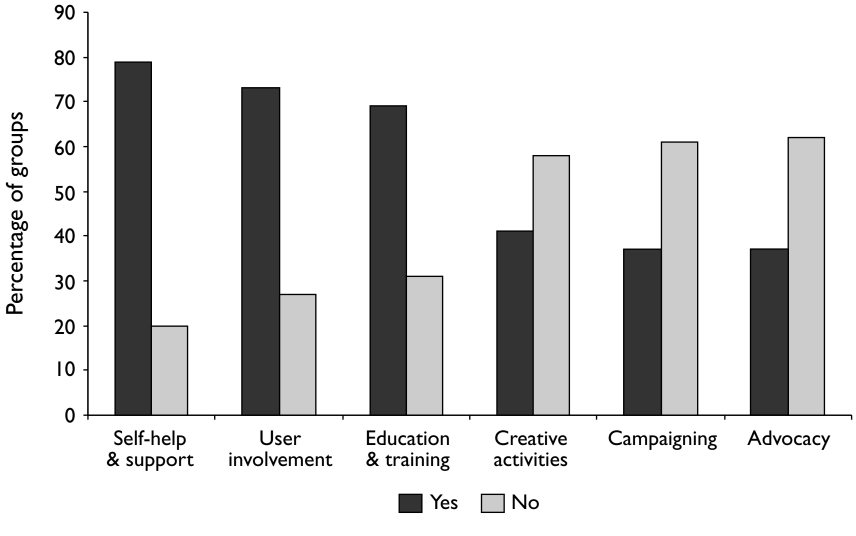
What do service user/survivor groups and organisations do?

To understand the movement better, we need to focus on what local and national groups do, and the problems and successes they identify. Our information comes from the postal survey of 318 local groups with a combined membership of around 9,000 service users/survivors, and from interviews, focus groups and visits to group premises. We spoke to leaders and project workers from six national service user/survivor networks with a total membership of 6,800 and 450 local affiliated groups.

Local groups' activities

The postal survey asked groups to state whether or not they engaged in six given activities. Figure 2 shows the response to those questions.

Figure 2 – Local groups' activities



Self-help and mutual support

The NHS and Community Care Act may have led to a rapid rise in groups coming together to be involved in decision making, but self-help and mutual support is still the main activity, being reported by 79% of local groups. The support offered by service user/survivor groups is likely to include elements of practical help with accommodation, employment, benefits advice and form filling, skills exchange, transport, meals and home repairs. It is also likely to include social support such as befriending, visiting when in hospital, drop-in sessions, social evenings, holidays, sports and leisure activities. Many respondents report that the support available helps people recover and move away from mental health services:

> *'I used to think self-help was a load of miserable people sharing their misery, making each other feel worse and it's just the opposite, it can be very uplifting.'*

> *'The 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.'*

> *'We've got people that came into their first meeting completely zonked on medication, they just came in, sat down, we made a cup of tea, they could smoke, fall asleep. Now we're seeing some of those people going to college and OK they're only doing a two-hour course a week but that's still massive.'*

> *'Self-help is a big part of recovery and self-management, and we've got about ten self-help groups, and we think the user movement should try and get funding for it because there isn't any direct funding for most small self-help initiatives.'*

User involvement

User involvement comes second to self-help with 72% of local groups taking part in some form of consultation with mental health professionals and decision makers. This can include acting as consultants and representatives, taking part in training or recruitment of staff, service monitoring and evaluation, user-led research and running local user consultation forums. Group officers explain that the persistence of their groups is making a difference:

> *'They definitely know we're here to stay, they can't get rid of us. Some people would like to think, "They won't stay for too long, too many meetings, we'll ignore them and they won't come back", but if you keep going to the meeting they think, "We can't get rid of them". Brick by brick, make sure you're always there and, if you've got any grumbles, you can always phone up the health authority, you've got to keep on at them all the while.'*

> *'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

The next most popular activity, with 69% of groups involved, is education and training for members and other external groups such as professional mental health workers. This can cover a wide range of activities, related to personal growth, recovery and getting a job, or skills for running groups or user involvement. Some groups have developed their own training courses:

> *'We train users who want to get involved in their service provider organisation. So everything becomes a bit more predictable and you're not on your own, that's part of personal empowerment.'*

> *'We do training in IT strategy and stuff like that which I think is really important for the non-profit sector.'*

> *'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 a social model which treats 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

Some groups are set up specifically to do creative work, such as survivors' theatre groups or poetry workshops, but many others have a creative aspect to their work. We found that 41% of groups reported some creative activities. Some pointed out the importance of retaining the fun elements rather than being swallowed up in user involvement and campaigning:

> *'We've done quite a bit of performing. We're into poetry, the three of us co-ordinators, and we've gone a lot into drumming and things.'*
>
> *'We have complementary therapy in the women's groups sometimes, people come in and do that and they come in and do this wonderful community singing and things.'*
>
> *'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

The survey showed that 38% of groups are involved in campaigning. Of these campaigns, the majority are on local issues such as getting the group known, campaigning for better or different services, challenging bad practice, fighting cuts and closures, financial issues such as charges for services, challenging discrimination and stigma, and increasing user involvement. Some groups also campaign on national issues such as rights, compulsion, the Mental Health Act proposals, electroconvulsive therapy (ECT) and as part of World Mental Health Day:

> *'Last year they were going to close the day centre here. The staff are good, it's very well run, people are happy there and we think it's brilliant, and also the crisis house, twenty-four-hour, seven-days-a-week crisis care. They were going to close the two because they had no money. We said to them, "We're not going to stand for this". We caused an uproar in the press, wrote letters, we just said, "You can't do it" and they didn't. The head of the PCT wrote us a letter thanking us for our support, in supporting her in trying to keep it open. Without our help it would have probably been closed.'*
>
> *'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.'*
>
> *'We're fighting against the psychiatrist labelling us and saying that we have these terrible mental illnesses. It does mess your life up if somebody in a very powerful position decides that you're a schizophrenic. If you've got that label you've definitely been damaged and you want to look at the history of the label and how it came to be.'*

Advocacy

The most usual service provided by local groups is advocacy, with 38% of groups involved in this. Advocacy work can be providing support for patients' councils in hospitals or working with people one-to-one.

> *'Advocacy is about making sure that everybody, whether they are being sectioned, an informal patient in hospital, or out in the community, whether they've had drug and alcohol related issues, or are on the streets, has the right to be heard. And if they 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".'*

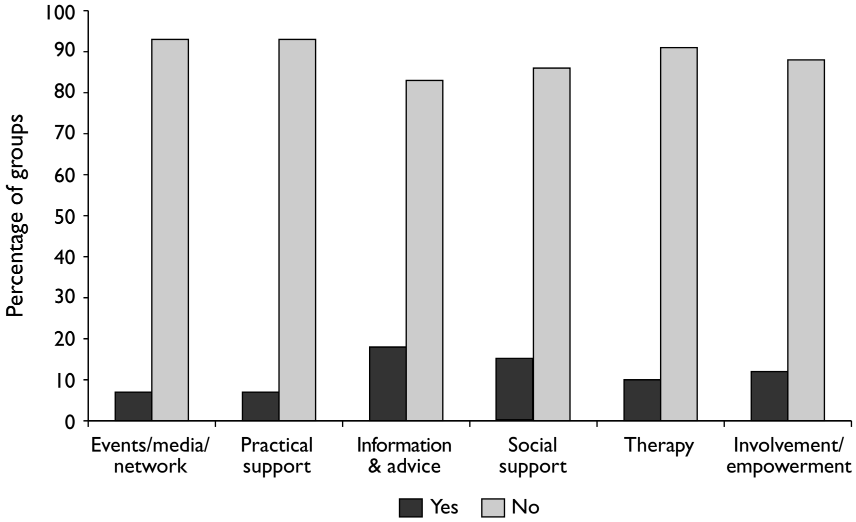
Service user/survivor-run services

Other types of services were reported by 28% of groups. These include drop-ins, befriending services, telephone helplines, social enterprises and recovery support:

> *'Giving a lot of people a safe space and people they can turn to who will understand, not question and be totally accepting, that's more important than anything else we do.'*
>
> *'We run a drop-in that operates every day of the year which I think is pretty amazing in itself. We've got a telephone helpline that operates every day of the year which is four hours every evening, although the funding for that is dicey at the moment, the continuation funding. We run groups, and a counselling service, so we've grown really. In some ways we're a bit like a MIND organisation except that we are completely user-run.'*
>
> *'We talk to people about setting up social firms, because we think they're important kinds of mechanisms for recovery. There's a lot of money around for social firms right now, you can get the community involved quite easily, you can get non-disabled people involved because they'll benefit directly from it.'*
>
> *'The main purpose of our group is for people coming from hospital or even in hospital, to give them an individual programme which will lead them to their desired goal. That may be simply to have an extended social life, or it may well be all the way to recovering a full-time job, not necessarily what they worked in previously but perhaps with assistance. It's the core part of our funding. The initial plan is to help 200 people within two years.'*

As well as reporting other services that they provide, 23% of groups additionally stated that they engage in other activities. The responses given can be grouped as shown in Figure 3.

Figure 3 – Other activities local groups engage in



As can be seen from Figure 3, groups do engage in other activities. These categories are based on the information given by the groups about other activities in their responses. The following list includes many of the things that groups said that they did and so shows what each category means as well as how many people said it.

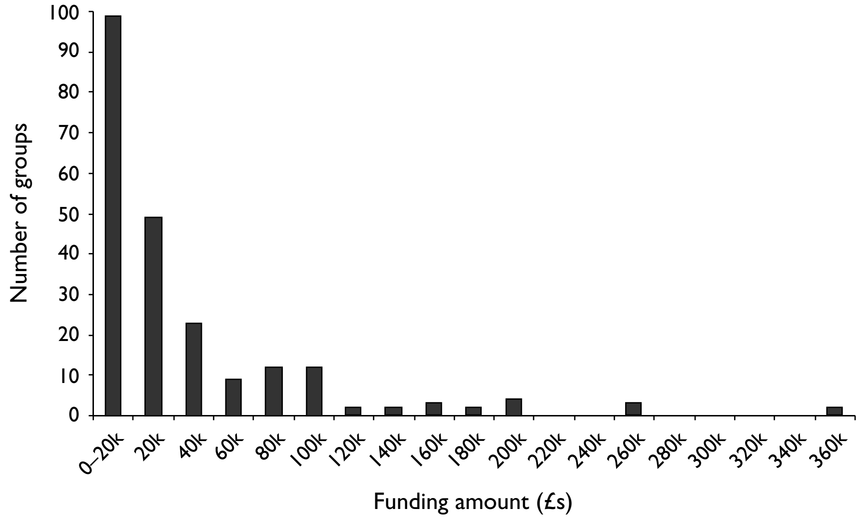
- *Events/media/networking (6.9%)*: Groups mentioned things such as: conferences; events; seminars; media work; publicity and promotion; networking; supporting user groups; fund raising; collaborative projects; communications; speakers (inviting, visiting); work in schools and the community (branches, development, support).

- *Practical support (6.9%)*: Things mentioned included: accommodation; employment; supported volunteering; financial assistance; referrals; skills exchange (Green time); benefits; form filling; bills; living skills; citizens' advice bureaux; providing a solicitor; mediation; travel; transport; café; meals and tea; library; decorating and moving people.
- *Information and advice (17.3%)*: This included: newsletters; magazines; website and internet access; information (gathering, sharing, leaflets, publications, dissemination, services, signposting and packs); advice; infoline and health promotion.
- *Social support (14.5%)*: Such as: befriending; hospital/home visits; visiting/counselling sufferers; outreach; drop-in; groups; friends' circles; activities; social (evenings, events, networking, therapeutic social activities, club and socialising); holidays; sport; leisure; music/TV/video and trips (minibus).
- *Therapy (9.1%)*: Such as: therapy (holistic, cognitive, therapeutic social activities); psychiatrists' sessions; counselling; visiting/counselling sufferers; complementary; rehabilitation; respite (caravan); crisis (support, beds); safe house; drug abuse; one-to-one support; mental/emotional support; love; acceptance and telephone support (helpline, support line, telephone counselling and support).
- *Involvement/empowerment (12.9%)*: Including: consultation; consultancy; representation; user involvement (including training, staff recruitment); empowerment (self, confidence building); quality monitoring; user-focused monitoring (UFM); service evaluation; research; user-run projects, initiatives; forums (open, user); service user insight; developing ideas on surviving the mental health system; self-education; employment in user-led services; valuing individuals; accounting to users; think tank/working party; awareness raising/stamping out stigma; crisis cards and improving services.

Funding of local groups

Clearly, what local groups are able to do relates to how much funding they receive. The majority of groups in our survey (78%) say that they do receive some funding, but the amounts in many cases are small and not secure. Most groups have to reapply annually for their funding. The amounts received range from £35 to £360,000 (see Figure 4) though concentrated at the lower end of the scale ranging between no funding and £40,000 per annum.

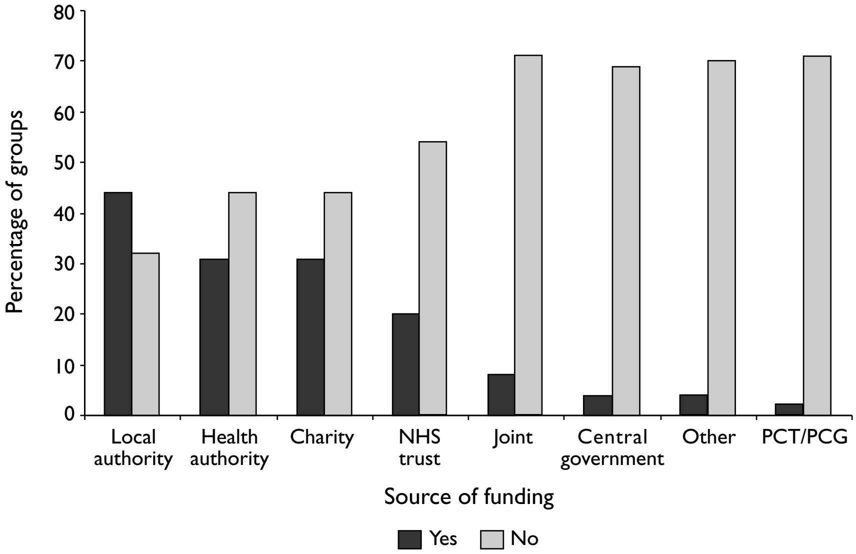
Figure 4 – Amount of funding received



Where does the funding come from?

As can be seen from Figure 5, most groups receive funding from local authorities (44%), followed jointly by health authorities (31%) and charitable trusts (31%) and, finally, from NHS trusts (19.5%).

Figure 5 – Sources of funding



What do groups spend their money on?

As shown in Table 1 (p. 4), the largest amount of money is spent on communication. It is not clear from the questionnaire how much of this is spent on keeping in touch with group members and how much on wider dissemination of information. However, it is an essential item for any group to stay in touch with its members so, presumably, much of this money is likely to be spent on mailings and telephone calls. The other main items: expenses and equipment, similarly, are basic maintenance activities. As only 38% of groups said they do campaigning, it is not surprising that this is the lowest on the list of items of expenditure. The other main items, paid workers and premises, are covered in more depth below.

Local groups: premises and paid workers

The majority (70%) of groups say they have some kind of premises. This may be a base to work from or just a space for meetings. Nearly 40% of groups with premises have a base to work from, usually in a voluntary sector building (58 groups) or statutory mental health building (25 groups). A further 20 groups privately rent their work base. Another 28% of groups who say they have premises do not have a place to work, but do have a space for their regular meetings, again usually in a voluntary sector building.

More than half of the groups (56%) stated that they have a paid worker, though most did not specify the type of worker or the number of hours they worked. From those that did specify, workers vary from an administrator doing a small number of hours to one or more full-time workers. Those who rely completely on volunteers often find this difficult. Those with paid workers were far more likely to have premises, to be engaged in user involvement and education and training, and to provide services to members.

Does the benefits system cause problems?

Groups were asked 'Is the benefits system currently causing you any problems regarding payment for members carrying out work on your behalf or on behalf of organisations you work with?':

- 39% stated there were problems;
- 47.5% stated there were no problems.

Of those groups who did mention problems, a number cited the difficulties for the individual members rather than for the group:

> *'The benefits system means that some of our members who would like to take on some work, but don't feel able to start full-time permanent paid work, are put off.'*
>
> *'Problem for users who take part in leading workshops, delivering training, etc.'*

Other groups mentioned the difficulties caused to the group:

> *'We ceased Therapeutic Earning payments because of jeopardy to benefits.'*
>
> *'We have to be careful about how much voluntary work we do.'*
>
> *'It causes problems when members can't come to meetings because of financial problems, they can't afford dinner, pay gas bills, etc.'*

How are these problems dealt with?

Some inform members or seek information, guidance and support:

> *'We advise our volunteers of restrictions.'*
>
> *'The trust has just launched a Payments to Users/Carers Strategy.'*

Some provide expenses only and others find ways to give payments within the legal limits:

> *'We limit payments to £15 per week maximum.'*

No benefits problems

Some of the groups that said there were no problems cited their lack of funding and therefore their inability to pay their members for work:

> *'No money – no problem!'*

Local group officers' and members' hopes for the future

Not surprisingly, when asked about the future, many people involved in running user groups hope for more money. They hope to find secure sources of funding so that their group can grow, find premises of their own and be able to reach out to more people. Another major reason for wanting more funding is to be able to provide services such as drop-ins and crisis safe houses:

> *'I'd like to see us owning our own building which would then give us the freedom to have a centre where we could do creative lifestyles, self-employment, have our own business employing people, whatever they want to do.'*

For some groups who presently rely on volunteers, an additional reason for wanting more money is to pay a worker. Others merely hope for a more stable and reliable group of volunteers or committee members.

Some respondents' main hopes are for greater equality, recognition of their issues and social change towards more spiritual value systems:

> *'Equality, valuing of Black culture and all cultures, respect, understanding and reparation of the damage being inflicted on Black communities in Britain's psychiatric system.'*
>
> *'I'm hopeful that there are more people getting interested in the spiritual side of things, looking at why we get out of balance with ourselves when we don't pay attention to our spiritual needs. I see the whole thing as a social problem really, it's this sort of lifestyle and the way we live in our country now, the way we live in the West is just appalling, rushed and materialistic and doesn't value people.'*

Do local groups network with others locally and nationally?

Figure 6 – Links with other organisations

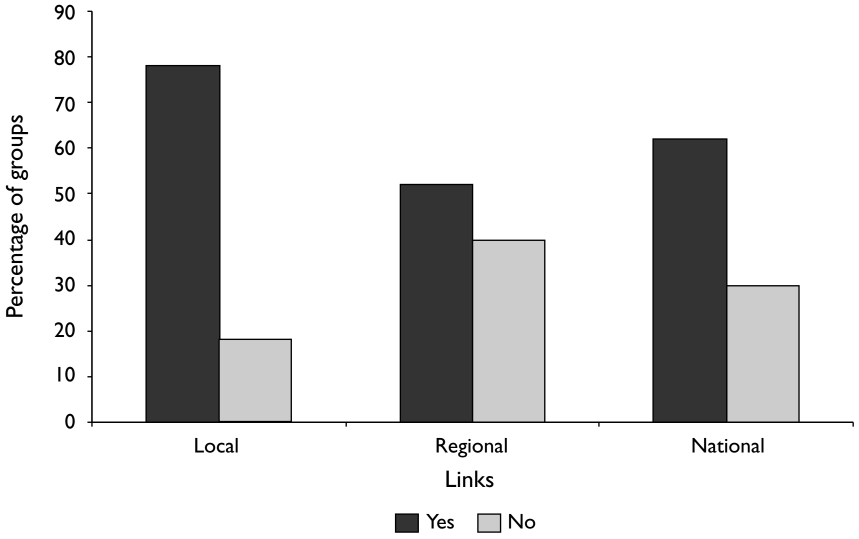


Figure 6 shows the response to a question asking whether groups have local, regional or national links. The responses were:

- 77% of groups have links with other groups locally;
- 52% of groups have links with other groups regionally;
- 62% of groups have links with other groups nationally.

The most common types of local links are with local branches of national mental health organisations, local user groups, user forums, advocacy projects and local voluntary organisations and forums. Much less frequent were reports of linking with statutory services, self-help groups or groups representing communities of interest such as those for women, people from minority ethnic communities, lesbians or gay men.

The most common regional links were with other regional user or advocacy groups and regional groupings of national mental health organisations. There were also some links with the new NHS regional mental health development centres and countywide statutory organisations and groups representing communities of interest.

The most common national links were with UKAN, MIND, the Manic Depression Fellowship and Rethink (formerly NSF).

National service user/survivor networks

Some national networks have been set up within larger voluntary sector organisations. Two of these are Mindlink, a national user network within MIND, and Voices Forum, a national network for people diagnosed with psychotic illnesses, within Rethink. These networks have a policy role within the organisation, but are expected to stay within guidelines set by the parent organisation. Those closely involved with these networks describe their situation as a mixed blessing, enabling service users/survivors to come together but inhibiting independence.

Boxes 2 and 3 give more information about these two important national networks.

Box 2 – Voices Forum

VOICES FORUM
(From an interview with the Voices Forum development worker)

Aims
To give hope and support to people who experience schizophrenia; help people recover through encouragement, advice and example; show the world how conquerable schizophrenia can be; dispel myths and eliminate stigma about schizophrenia, especially relating to violence; describe schizophrenia from the point of view of people who have experienced it; help service users, carers and professionals speak the same language (formulated at the first meeting of Voices Forum in 1986).

Membership
About 500 service user/survivor members across the UK. The gender ratio is two to one in favour of men. Members are mainly people with experience of schizophrenia. Ethnicity is not currently monitored.

Structure
Voices Forum is part of the Rethink charity and is based at its central offices. However, it has the right to take policy positions independently from the parent organisation. Meetings are held quarterly in Birmingham and are open to all members, who receive travel expenses. Meetings are for service users/survivors only. They are the main decision-making body of the Voices Forum. There is an elected chair and vice chair and treasurer. Voices Forum manages its own budget, which is negotiated annually with Rethink.

Activities
Voices Forum has representatives on committees within Rethink and on the Board of Trustees. It is represented on interviewing panels, and members contribute to Rethink's external conferences and training courses for a wide range of professionals.

Producing and providing information for members: a small number of local Voices groups exist to provide support and social activities. The Forum networks with other service user/survivor networks, e.g. UKAN, Hearing Voices Network and Mindlink.

> *'When people phone up looking for user groups in their area, we refer them to groups listed by the Hearing Voices Network and UKAN if we don't have one of our own groups there.'*

Achievements
Some members of Voices Forum are interested in self-management. The Forum organises 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.

continued

The Voices Forum magazine, *Perceptions,* and its website provide an outlet for members' creativity.

> *'Rethink has a target to increase the proportion of its members who are users to 30% at least and to increase user membership of committees.'*

Voices Forum has been represented on the research group developing schizophrenia guidelines for the National Institute for Clinical Excellence (NICE) and has been a member of the core group of the Mental Health Alliance.

Problems
Rethink is historically a carer organisation, so the user view is sometimes a minority view.

> *'Working within a non user-led organisation mostly works well, as Voices has a basis of independence to develop its own ideas, but, in terms of an external profile, it probably means we get a bit submerged because obviously Rethink is a much bigger organisation.'*

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

Box 3 – Mindlink

MINDLINK
(From an interview with the Mindlink co-ordinator, Madie Chapman)

Aims
- involvement in MIND's policies and campaigns;
- information sharing;
- personal empowerment;
- encouraging creativity.

Membership
Membership is free to all service users/survivors. The membership was 1,700 at the time of the interview, but all members were being asked to reapply (to ensure that people were making an active choice to belong). Estimated membership after the reapplication process: 1,000.

Structure
Funding is mainly from MIND with occasional external funding for specific pieces of project work. Two staff – a co-ordinator and an administrator, plus volunteers. National advisory panel elected by the members. The terms of reference were being rewritten at the time of the interview, because of changes in MIND's structure (closure of regional offices). The new panel will have a smaller proportion of members representing regions, but others representing communities of interest, including Black and ethnic minorities, lesbians, gays and bisexuals, disabled people, younger people, older people, and rural and geographically isolated members.

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 to 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.

Achievements
Ensuring members are involved in MIND policy making, which is now routine practice. The activities of Mindlink and the mutual support available are confidence building for members.

continued

Problems
Achieving diversity: progress is being made, measured by regular monitoring of ethnicity, gender, sexual identity, languages, disabilities and age, but more needs to be done to achieve a more diverse membership.

Working within a non-user-led organisation can be difficult. However, MIND is changing, with an increasing proportion of staff and Council of Management members openly talking about their personal experiences of mental distress.

Some members see MIND, and Mindlink, as insufficiently radical, while others are upset by what they see as Mindlink's over-critical attitude towards psychiatry. It can be a difficult balance for the co-ordinator to keep members with different views on board:

> *'People have written to us and said, "Look, I really don't want to be part of your organisation any more, you're ruffling too many feathers". Equally we have a number of people who say, "Come on, you know you've got to be much more actively involved, it's so frustrating", and I can sympathise with that as well, but I think, by having spaces for everybody to have their say, however radical or non-radical that might be, and being tolerant, we can work together as a much bigger group.'*

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

Independent national networks

We talked to leaders and paid workers from four national independent service user/survivor organisations: UKAN, No Panic, Mad Pride and Voices Forum. We also spoke to Tony Russell, the head of Breakthrough, which has been widely regarded as representing service users. Tony made it clear to us that Breakthrough is in fact a small company with no claims to represent others:

> *'I wouldn't call us an organisation, we're just a little user-led research and training organisation/group/company, we don't claim and never have claimed to represent other users.'*

The organisations in Boxes 4, 5, 6 and 7 do claim to represent a large number of service users and survivors. Each one has developed consultation mechanisms such as newsletters, websites and committee structures to involve as many people as possible.

Box 4 – UK Advocacy Network

UK ADVOCACY NETWORK
(From an interview with Terry Simpson, manager of UKAN at the time of the interview)

Aims
- promoting user-led advocacy groups;
- education and training;
- wider world issues;
- user involvement.

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

continued

Structure
There is a national management committee. The membership of this is becoming more diverse. The gender balance is about equal and there are some Black members and gay members. Decisions about the organisation are made at the annual meeting. The groups that form UKAN are in control. Management committee members run the organisation in the year in between the annual meetings. There is a manager and four part-time workers. Most of the funding comes from the Department of Health Section 64 grant and the rest is from the Voluntary Sector Trust. UKAN is a registered charity and a limited company, and has rented premises in Sheffield.

Activities
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.

Achievements
UKAN has worked to increase its diversity, by providing anti-racist training for the management committee and having a policy of making contact with Black groups and including them in outreach, training and publications. It organises training for advocacy groups, producing a Code of Practice on Advocacy in 1994, and more recently the Advocacy Training Pack, and *A Clear Voice, A Clear Vision*, a book of articles on advocacy.

> *'We've been there for seven years now and we've grown in that time. We've provided consistency. I think that we have had a role in bringing people together in the user movement. For example, when we organise our annual meeting, we try and get other national bodies there. We try to build the movement as well.'*

Problems
It has proved difficult for UKAN to bring national movement organisations together, apart from on one occasion a couple of years ago when nine different national user groups were represented in discussions concerning the proposed changes in the Mental Health Act. User involvement requests are often given with deadlines that are too short for the workers to contact people and find someone to take part, and payment is often not offered.

> *'For representation on other bodies we rely on the volunteers on our management committee, and, if they're not getting paid for it, it might be at least a whole day to go to London and it can be quite a heavy meeting and then getting home again. Why would somebody do that? They must be incredibly dedicated.'*

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

Box 5 – No Panic

NO PANIC
(From an interview with Colin Hammond, the founder)

Aims
Self-help for people suffering from anxiety disorders including phobias, panic attacks and obsessive compulsive disorders.

Membership
Over 3,000 people with a diversity of backgrounds.

continued

Structure
No Panic is a national charity. It has one part-time co-ordinator and 87 volunteers. It operates from the founder's home. It is user-led. There are monthly management meetings. Funding is from voluntary donations and a £10 a year membership fee.

Activities

- No Panic is represented on the panel formulating procedures for NHS Direct. Some MPs are members. Members sit on regional health advisory boards.
- Building a helpline; telephone groups; producing literature, booklets, audio tapes, videos, etc. Literature is produced on tape for people with reading difficulties and in a variety of languages. Taped versions in different languages to be produced shortly.
- Groups meet regularly throughout the country, some link by telephone because their problems prevent them from getting to self-help groups.

Achievements
Giving people hope via the helpline, literature, tapes, etc. based on self-help techniques. Over 100,000 free information packs sent out. The helpline deals with up to 25,000 calls a year. The organisation is raising awareness by sending information to health authorities and professionals such as psychologists. They are involved in a pioneering project with the Institute of Psychiatry, training volunteers to work in the new primary care units.

Problems
No secure sources of funding. There are some grants from local councils and health services but not on a regular basis. There are problems communicating well with people who speak languages other than English, even with translation. 'Panic attack' doesn't translate into Punjabi or Urdu.

> *'We're trying to word our tapes and literature in such a way that people will understand what we're talking about.'*

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

Box 6 – Mad Pride

MAD PRIDE
(From an interview with Pete Shaughnessy[5], one of the founders)

Aims
Political action and creativity.

Membership
Mailing list of about 300 people.

Structure
Core group of about eight people, though more get involved when particular events are being planned.

continued

---

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

Activities
Demonstrations and music events. 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, and many users/survivors felt this was not something to celebrate:

> *'It was a commemoration on the steps of St Paul's Cathedral, because they were going to have a celebration, and we wanted a commemoration to the people that had died, they were like celebrating the system, and there was like people that died from the system.'*

> *'Mad Pride is overtly political. We're telling people, "Look we're mad and we're not ashamed of it", we are psychotic patients and we're not hiding that fact. We put on gigs and we'll have leaflets and maybe we'll make a few little speeches, remind people what it's about. We put on an event for £100 and then make our money back on it by people paying at the door or by making donations, so it's much cheaper than running a conference and probably even as effective, people go away feeling good.'*

Achievements
Mad Pride held a demonstration outside the office of SANE (Schizophrenia A National Emergency):

> *'They were putting out misinformation, like everyone that's mentally ill if they don't take their drugs they're going to be dangerous.'*

Protest march against the Royal College of Psychiatrists' anti-stigma campaign:

> *'Our idea behind that was, hang on a minute, they're the ones that caused the stigma, they're the ones that give people labels, it's crazy.'*

Over 2,000 people attended an all-day music festival run by Mad Pride in the year 2000 and the Mad Pride book sold out its first edition. The Mad Pride website, which was launched around the same time, hosted the UK Survivors' mailing list, the first electronic network for service users/survivors. These activities helped in reclaiming the term 'mad' and celebrating the positive side of madness.

Problems
No Black people are involved in Mad Pride's core group, though Black groups have played at music events:

> *'We don't want to co-opt people for the sake of it. There are some Black users out there that complain that they're always getting co-opted because they're Black, rather than because of what skills they've got or what interests they've got.'*

Mad Pride website:
http://www.clono.freeserve.co.uk

Box 7 – Hearing Voices Network

HEARING VOICES NETWORK
(From an interview with Mickey Devalda, Chair)

Aims
Providing information and support for people who hear voices. Working with the media to raise awareness and understanding about voice hearing, providing education and training.

continued

Membership
A mailing list of 1,300 people who receive a quarterly newsletter and 150 local Hearing Voices support groups. Members are currently more men than women, all age groups. Most members have been diagnosed schizophrenic or manic depressive, but some have had no diagnosis. Efforts are being made to increase minority ethnic membership.

Structure
A paid worker and a committee. The office and the worker are currently managed by Voluntary Action Manchester, because the organisation does not yet have charitable status, though is applying for it.

Activities
Producing a newsletter and running groups. People have a variety of different explanations for their voices and support is available for them to explore their own perspectives.

Getting articles into the media and responding to subsequent phone calls from media and the public. Speaking at conferences:

> *'People phone us up wanting to know more about it. This morning I've come into the office and somebody wants a service user at a conference in Nottingham, it will probably be me and I'll go down there and bend their ear for an hour and a half. I think I shall prove that I'm certainly not mad in spite of my voice hearing experience and I'll be speaking up for everyone else as well.'*

Providing training to community psychiatric nurses (CPNs), support workers and approved social workers.

Achievements
Setting up 150 support groups and a wide support network:

> *'Some of the people on our mailing list connect to another 20 or 30 people that are associated with that one person that's on our database. So we must be reaching thousands of people, and I'm sure that without knowing it we've saved lives.'*

Public education

> *'I get people saying after a training session, "You've bowled me over", and things like that, especially younger people, they really understand our message because a lot of people in Hearing Voices used to be into drug abuse.'*

Problems
Currently too male oriented and not succeeding in attracting many minority ethnic members, despite efforts to do so:

> *'I think Black people experience racism within their own lives and that's a big enough problem to deal with.'*

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

Summary of what service user/survivor groups do

- The most popular activities for local groups are: self-help and mutual support (79%), user involvement (72%), education and training (69%), creative activities (41%), campaigning (38%), providing advocacy (38%) and other services (28%).
- Most local groups have at least some funding, usually from statutory organisations, but this is often small-scale and insecure. Most have a place to meet or somewhere to work from, and often this is space in a voluntary organisation.

- Local groups commonly hope for a better funding situation, more security of funding and a larger amount, usually to have premises of their own and a worker to enable them to reach more people. They also hope to influence society and create greater understanding and awareness.
- Local groups generally network with other local groups, with national service user/survivor networks and national mental health voluntary organisations.
- National networks offer information, support, education and training for their members, the media, the public and mental health professionals. Some support a network of local groups, others work within major mental health organisations. Some have representation on major national policy-making bodies.
- Typical problems for national networks are: lack of diversity of membership, though some are making substantial efforts to address this; insufficient funds to meet members' needs; lack of independent identity (for those within non-user-led organisations); demands for user involvement with insufficient time and resources offered; and lack of opportunities to meet with other national networks.

5

How representative is the movement?

Does the movement represent 'ordinary' service users?

Many of us have been accused of not being typical users. We are told we are too articulate and educated, or too angry and radical, too well, too ill, or in some way different from the majority of 'ordinary' service users. Most often that accusation comes from professionals, but sometimes it comes from other service users/survivors. It can leave us rather confused. Who are the 'ordinary' service users? Are they the ones with the most severe and acute problems, which leave them too vulnerable to cope with involvement? Or are they people who are being made better by their treatment and don't wish to complain? Are the critics genuinely concerned about representation of service users/survivors with a wide range of experiences, from diverse cultures and backgrounds, or are they more concerned with invalidating criticisms they find unsettling? We found that there are issues of diversity that the movement needs to address, but that professionals often make unrealistic demands without offering the resources to develop the movement's capacity for representation.

Are individuals who speak out unrepresentative because they don't really have problems?

Maybe the opposite is true. Some respondents suggested that those who speak out are often the ones who have experienced the most serious problems and invasive treatments:

> *'When I was in a permanent crisis I couldn't possibly have gone to a committee meeting or spoken at a public meeting, I could no more have done that than flown to the moon, but I do have that experience of being nuked for months at a time, so I know what that's like.'*

If this is the case, then many of those who are currently unable to speak out may be the spokespeople of the future, given enough resources, encouragement and opportunity.

Do service user/survivor groups and organisations represent ordinary users?

Is the movement made up of people with worse than average problems, who are angry because they have received more invasive treatments, such as forced medication? And, if so, does this expressed anger put off people who value and need treatment? Some respondents think the movement used to be more angry and radical, but say that this is now changing, with more people involved who have never been inpatients:

> *'I think the user movement has to be representative of the different ways in which people go through the system, but it hasn't got enough people who've been totally damaged by the system, and that to me was what it was at the beginning. The people who were active were angry because they had been doped up to the eyeballs for years and years and years. A couple of courses of Prozac and two outpatient appointments in psychiatry don't seem to me to amount to the same thing.'*

The above statement indicates that there can be competition among service users/survivors about who has suffered most, which can be damaging to the movement's solidarity and cohesiveness. This type of conflict may result from lack of opportunities for service users/survivors to come together to discuss their different experiences and views. It may also indicate that divisions relate to the changes in services over the past 20 years. Those who have been in the movement for many years need the opportunity to hear about the experiences of those newer to the movement, whose main experiences have been during the era of community care and short hospital stays, which may raise different issues:

> *'People say, "Oh no, you're not a proper user because you were never compulsorily treated", or "You're not a user because you were never in hospital", or "You only ever took minor tranquillisers and not major tranquillisers". I think we shoot ourselves in the foot by emphasising these sorts of differences.'*

Some service users/survivors do think that the movement is limited in its ability to involve or to reflect the majority of service users. A picture emerges of divisions within the movement, and also between movement activists and the majority of service users, based on different levels of activism, confidence or opportunity, and differing class and cultural origins. Some respondents are worried that the movement is too much concerned with political change and forget that many still need ongoing help and support, from services and/or from other users/survivors:

> *'I've got a lot of concern about service users who have serious issues affecting their lives that are causing them a lot of mental distress and they need some help. But sometimes I feel that's not allowed to be expressed within service user groups because you're meant to be all fight and all campaign and anti-meds, and that's fine as long as there's an alternative where people can still access something.'*

There is concern about people joining the movement for their own benefit and ignoring more collective issues:

> *'I feel that a lot of people go into the service user movement for their own benefit, but it isn't really just for them, is it? And I think this may be why it isn't going forward in some ways.'*

Perhaps the majority of people who use mental health services have never even heard of the movement. Many may be unhappy with treatment but feel powerless to make a difference. This view would suggest that better information about the movement would bring about greater representation of 'ordinary' service users:

> *'Probably 90% of service users don't know anything about the service user movement. I think a lot of people are in the system and they don't think it could be very different. They just accept whatever happens to them because they are desperate and want to get better.'*

The national movement is sometimes seen as out of touch with its own grass roots:

> *'The movement is a group of middle-class, well-educated service users who were around in the early 1980s. I don't know how much relevance it has to most service users in reality or even to most service user groups, actually.'*

Even some people in local groups may feel out of touch with the national movement:

> *'If you look at it from our perspective, whatever is going on never filters down, so we never get the benefit of anything that any kind of national movement is doing. It seems to us that people on the national stage are following their self-interest and not really representing anyone else.'*

While the above comments show that there can be poor communication between people working at a local and national level, the following comment expresses an understanding that many groups rely on committed but fragile individuals, and that, without a strong infrastructure, even national organisations may be vulnerable:

> *'It is quite sad that you have some very good organisations that rely on the dedicated work of a small number of people. It only takes one of those to fall and where is the organisation? I suppose the difficulty and fragility of the survivor movement is that so many of the best people are at risk and it's difficult to give everything and then see it dissolve because of your mental status.'*

Can people still be representative if they get paid?

The inevitable differences within the movement can be exacerbated when money is involved. Service users/survivors who work as advocates or consultants, user-involvement workers, those who run user/survivor organisations, or even those who spend most of their time working for the movement in a voluntary capacity are sometimes accused (by mental health workers or by fellow service users/survivors) of being 'professional users' and therefore unrepresentative of 'ordinary users'. It is good that there are many more opportunities for empowered service users/survivors to find paid work in which they can use their skills, experience and commitment. But this can then put them in an awkward position, where they are neither accepted by their fellow professionals, nor by those still caught up in the system.

This finding is confirmed by a recent report (Snow, 2002) that shows that survivor workers often face discrimination at work.

Several respondents described how they had gone from being unemployed service users to paid workers through their work in the movement, proudly accepting their new role as professionals:

> *'Here you've got service users, a lot of whom have not had work – certainly not had valued jobs, and suddenly they've got an opportunity to actually work and be employed in the mental health services. Would you rather be a mental health professional or a mental health service user? I think I would probably rather be a mental health professional – certainly in terms of status and income.'*

> *'I am a professional user. I'm self-employed and a lot of the work I do is as a service user. When I started doing user involvement with my local mental health services, I was really lacking in confidence. As my confidence increased I needed to work, and my choice was to leave the field altogether and no longer be able to contribute, or to become self-employed and be a professional user. I see lots of people begin to get confidence and then go and get jobs elsewhere. That's a good choice, but some of us really do feel passionate about it and want to stay in the field.'*

Another pointed out that being called 'professional' is not necessarily an insult:

> *'It's a lovely compliment to say I'm professional. I don't worry about it, people use it in the disparaging way to say, "You're not a typical user", but then nobody is typical, and with user involvement you'll need skilled people to sit on NHS trust boards or planning boards and the rest.'*

However, being paid can put service users/survivors on the other side of a divide:

> *'I think we should be demanding and be paid, so that those of us who choose to work can do so and that our skills and expertise are recognised. But then often you can get a lot of flak if you are being paid and it's very difficult working with people who aren't, who are on benefits.'*

This raises the question of whether people can be paid to represent others, or does the mere act of paying people render them unrepresentative? Perhaps the problem is with the expectations and demands of the service providers and commissioners who are paying. Are they going about this wrongly, and putting service users/survivors in a no-win situation?

> *'What "professional user" means, in a derogatory way, is that you're going to the same people all the time and using them as a voice of users. It's unfair for them and unfair to other users. It puts someone in a difficult position, and what happens is they become ostracised by other users, they work in a vacuum. Often you get people asking me, "What do users want?" I say, "Why don't you ask them, it might be better to go and ask them".'*

There is also a danger of losing one's independence if one is paid by service providers:

> *'If you're earning a living servicing the mental health system, how hard are you going to be criticising it?'*

One respondent expressed concern over the trend to set up user involvement projects and employ workers who are then seen as the voice of service users, whether or not they have been service users themselves:

> *'When actual users turn up they say, "You're not representative", and yet they like talking to paid user involvement workers. I think user involvement projects should be run by users, managed by users, and the agenda should be set by users, not the funders. The actual people who are disempowered now are more so and what we've got now is a cabal of the usual suspects. If you go round some of the patients' councils talking to people, how many patients are on them? They're often ex-patients and very articulate ex-patients, where what's really important is to hear the voice of people actually on the wards. I think it's an issue that the user movement has to face up to.'*

But co-operative working relationships with mental health workers do not necessarily mean 'selling out':

> *'I don't think it's good of any advocacy project to deliberately get people's backs up. We do get people's backs up a lot, but I think when someone, a key worker, a psychiatrist or someone, has helped me with a client I will say, "I really appreciated your help". It's not about colluding with them or bowing down to them, but there has got to be mutual respect and a working relationship.'*

Finally, perhaps there is an ongoing process whereby people do what is appropriate for them at different stages in their life journey, and then move on to other roles. Problems arise only if the same people continue to be seen as representing current service users, leaving no room for new people to take their place:

> *'There tend to be some focal figures and I don't want to be that. I'm hoping that I can do stuff and then somebody else can come up and do their stuff and someone can come up behind us. But what I see at the moment are certain individuals who are constantly promoted – you've just got to look at conferences to see that.'*

The gap between the movement and ordinary users is not that great

Some argued that, even though many people who receive or use services are not involved in the movement, their views are not necessarily different from those who are. Some groups make an effort to find out and represent a wide range of views:

> *'We're a real mixture of ex-service users and service users. I go to a day hospital and about once a year I have a holiday in the local hospital. So I talk to other patients about their issues and try to pass those issues on. I think we do represent the views of people who don't want to speak up.'*

Those who get involved with user-led research, such as user-focused monitoring have an opportunity to find out how well the movement reflects the views of local service users:

> *'It was gratifying to hear how much the views of people we interviewed echoed our own, and to know we're not just arguing our own case.'*

Does the movement reflect social diversity?

Perhaps this is the most important, but the least frequently asked question regarding the representativeness of the movement. Given the multi-ethnic nature of contemporary Britain, accessibility and rights for all people, regardless of their particular identities, are key issues of our time. The rise of liberation movements for women and minority groups has drawn attention to the multitude of ways these groups have been oppressed, including by the mental health system.

Most of us who have been through the mental health system have experienced prejudice and discrimination and want the movement to challenge it. We know what oppression looks like, what it feels like and the effect it has on our lives. We don't want to mistreat others the way we have been mistreated ourselves.

We asked respondents how well they think the movement is doing in terms of including people from groups that experience prejudice and discrimination. In particular, we asked about Black people, women, lesbians and gay men.

Black people

As shown in Table 3 (p. 7), Black respondents don't tend to feel part of the movement or think it has much to offer them, and are seeking to develop a movement of their own. These views are based on experiences ranging from isolation and lack of encouragement to outright racism from white users:

> *'I've had more racism from white users than from white professionals.'*

> *'When I go to conferences, all I see is white faces staring back at me – I don't see Black faces at all.'*

A number of Black respondents became involved in the movement by joining general user groups but then gravitated towards specific Black groups because their issues of concern were not being addressed:

> *'I got involved mainly in the white user group in X hospital. For a long time I was the only regular Black person who was in the group, and it was not too bad because I'd got used to being the only Black person in situations. Then I started getting a bit more involved with other Black service users/survivors and started feeling, "Why don't we have a discussion with these issues within our user group?" We decided it might be nice to get together separately where we could address our issues, because it just didn't happen in the user group, and for us it was too much of a challenge to raise those issues.'*

Generally, white service users/survivors acknowledge that the movement hasn't been an easy place for Black people to be:

> *'There is often an assumption that Black people aren't interested, which I don't think is true at all. If people expect something to be white and exclusive, then why would they get involved in it, and I think the service user movement has that reputation.'*

One white respondent blames Black people for not getting involved and we have included the quote because it illustrates the attitudes that deter Black service users/survivors:

> *'The ethnic groups tend to keep themselves to themselves. It's very hard to get them to join in with things. The ones I've talked to say, "Nobody wants to listen to us". We do want to know what their opinions are but the only way we are going to find out is to have the groups come along.'*

But some Black respondents have had support from some white people:

> *'It was white users who first got me involved.'*

And some recognise what the movement has been up against:

> *'The white movement has been challenging for the social model against the medical model, so I don't want to bash them because it's taken them a long time to get listened to by the professionals.'*

Gender issues

In contrast to the views on Black people and the movement, most respondents think women are well represented. Fourteen thought they were well included or even over-represented, six thought that not enough was being done for women and five thought that men were losing out and their issues were being neglected. The following quotes illustrate each of these positions:

> *'I find women are very well represented, especially nationally. I'd say it was 75/25% female from what I can see.'*

But a Black woman commented:

> *'I don't sometimes take on women's issues even though I'm a woman, but I'll take on the Black thing or maybe the Black man thing, even though I'm not a man. But because they're sort of dominating in the system, I'll be going on about them and then realise, "Oh, I haven't done anything about Black women".'*

And a man said:

> *'The service user movement should recognise there are issues around men, children and mental health. If you've got a mental health problem, you've got no hope of being able to have any contact with your children if your family has been affected by your illness, which it normally has.'*

Perhaps the key point raised in the responses to the question about women's involvement is about how people can talk about issues that don't affect everybody but do affect them, be listened to and understood, and have those issues taken up by others on their behalf.

Sexuality

Group officers are unsure how well the movement takes into account the views of lesbians and gay men. Eight group officers said they were unsure, six felt that more could be done and six felt that substantial efforts had been made.

What comes across most clearly, in the interviews, is that most respondents haven't thought about it very much and this passive attitude is a problem for people who, because they are lesbian, bi-sexual or gay, have to deal with prejudice and discrimination:

> *'The service user movement barely talks about it at all, which mirrors the rest of the world. People treat sexuality as something that shouldn't be talked about. It's not about who you sleep with, it's about who you emotionally connect with and it's about living in a very heterosexual world.'*

One respondent, who felt their group was welcoming to a lesbian member, demonstrated their unconscious prejudice by saying:

> *'She felt quite at ease with us and would openly talk about her partner. We were just as accepting as we would be if she was describing hallucinations.'*

Why not be as accepting as if she was talking about a male partner?

But there is one group where prejudice is actively challenged:

> *'If people come into the group and say things that are unacceptable we actually say, "These things are unacceptable", whereas other groups aren't necessarily as good. The patients' council used to be awful. They've got a different worker now but their first worker was very sexist and wasn't very good on sexuality issues, either.'*

Approaches to diversity

We found two distinct attitudes towards diversity, the first emphasising underlying unity, and the other recognising and valuing difference. We will look at these in turn.

1. We should all unite under the banner of 'mental health', focusing on similarities rather than differences
Some respondents suggest we will be more effective if we emphasise that mental health problems can affect anybody:

> *'Instead of saying, "I'm in this group", "I'm in that group", let's let the world see we are united together. After all, we are all trying to get the same thing – recognition that mental health problems happen to anybody. It happens to kings and it happens to people who sleep in shop doorways. It doesn't just pick on people from minority groups, it picks on everybody.'*

With this attitude, there is sometimes a belief that having had mental health problems makes you more sensitive to other people who have been badly treated by society:

> *'People who have been through mental health issues know what it's like to be stigmatised and alienated by so-called normal society and have more empathy with groups that feel they are alienated.'*

There may be some truth in this but it doesn't automatically bring us together as one happy family of service users/survivors. What do you then do if people from minority groups don't choose to join in with you? There can be a tendency to blame them:

> *'That's what I was saying about the coloured people – there weren't that many at MIND. Perhaps they don't bother but the ones that were there had a chip on their shoulder.'*

(This quote is offensive to Black people and use of the term 'coloured' is particularly so. We have used it because it illustrates the insensitivity of the 'one-banner' approach.)

But over-emphasising diversity can stop us seeing the bigger picture, as this Black service user suggests:

> *'I've been to a number of things over many years where people talk about racism in psychiatry and then I think they overlook the fact that it's not just that psychiatrists are racist, it's the fact that psychiatry is crap anyway. If you took away all the racism it would still be an inappropriate system.'*

2. We should accept that people do have different experiences, and may find it difficult to work together. We can then look at ways of forming alliances, with the majority group taking responsibility for reaching out to the minority group
People who are already in the majority in service user/survivor organisations, however small and insignificant they feel them to be, need to accept that they should be reaching out to people who find it less easy to join in:

> *'We've got to make it safe for women, for people from minority ethnic communities, lesbians and gay men, people with physical impairments as well. We have to take these issues on, otherwise people will not feel the service user movement has anything to offer them.'*

And:

> *'We can only do this by talking to people, finding out what their needs are and accepting that people have different needs.'*

This can be done, for example, by:

> *'Networking with other organisations, perhaps getting invited for a talk. They might have a social club where you can just talk one to one.'*

What needs to be done about diversity issues in the movement?

Perhaps the key to success is to accept and celebrate both our differences and our similarities. We need to find a balance between working separately and together:

> *'It would be great for there to be a general service user movement with scope for things to be separate if necessary. Ethnic minority groups may choose to meet separately, especially where there may be language issues or issues around gender and stuff like that. But I think it would be a shame for there not to be some sort of forum where service users from all backgrounds meet up together, it would be much more powerful, if it were possible, for people to come together as a united movement.'*

It is useful for service users/survivors from majority communities to think about what enables us to participate successfully in a group where we are the minority, such as a group of professionals. We feel better if professionals understand that our experiences are different from theirs and that we may have a different view from them, and if they take responsibility for making it safe for us to join in and speak up. If we then apply the same principle to encouraging the participation of people from minority groups in our own organisations, we will make progress:

> *'We need to move away from the idea that the world is some kind of homogenous group whose needs are all the same. For me, we need to ask how does this affect women, how does it affect Black and minority ethnic communities, how does it affect anyone who's disabled, anyone who's lesbian or gay?'*

We need to build on the successes we have had and recognise it will take time to fully include everybody in the movement:

> *'We've really prioritised making contact with groups that in the past we haven't necessarily been that successful at engaging, like Asian users and particularly deaf users as well, and that's paid off in a big way. We do go out of our way to make sure that we are representative, and something like 55% of our members are from Black and ethnic communities. A high number are African/Caribbean, just over 50% are women, we have some members who identify as having physical impairments as well, and issues around sexuality are talked about a lot more since I arrived!' (Group co-ordinator who is gay)*

Summary: issues of representativeness and diversity

General issues

- The quality of the movement rests on its ability to reflect the wide range of people who are affected by mental health problems, treatments and social attitudes about mental illness.
- There is no such thing as the 'ordinary' service user. There are a wide range of personal experiences of mental distress and use of services, compounded by different racial and cultural backgrounds, gender, age, sexuality, disability and social class.
- At present, the movement is limited in its ability to respond well to this diversity, though some individuals and groups are making efforts to reach out to minority groups.

Issues of representation

- The movement was formed mainly by people who had had severe problems and painful experiences, both with their mental health and with the services offered. Anger is a common motivating factor. Ability to be actively involved reflects the extent to which people can rise above their problems, even if the problems are ongoing. Given information, time and resources, active involvement can be a valuable option for many more service users/survivors. Active involvement should not be grounds for dismissing people as 'unrepresentative'.
- Services are changing from mainly large institutions to more community-based, and the movement needs to reflect changing experiences of services.

- It is right that people who have been devalued and stigmatised because of mental health problems can put their skills and experience to good use by working in mental health. They should not, however, be expected to represent all service users, unless properly resourced to do this, for instance by funded consultation or good quality research.
- Actively involved service users/survivors who have researched the views of local service users report that the gap between their own views and those of non-activists is not that wide.

Specific issues of diversity

- Black service users/survivors are not finding the movement is addressing their specific issues. This is leading them to want to organise separately, perhaps relating more to other Black organisations than to the movement.
- Women's issues are reasonably well represented in the movement, though Black women's issues less so. Few people are talking specifically about men's issues and this may need more attention.
- Sexuality issues are currently not well understood in the movement, and more work needs to be done to raise awareness.
- While some respondents advocate a unified approach, where differences are ignored in favour of concentrating on issues in common, this may lead to the neglect of specific concerns of marginalised groups. It is better to acknowledge and celebrate differences, encourage and support people to meet separately where needed while taking care to offer opportunities for inclusion in the wider movement.

Black service users/survivors organising

The existing Black service user/survivor movement

Black service users/survivors think that there is an emerging Black movement but it is very fragmented at the moment. There is a need for groups to come together to support and sustain one another and some evidence shows this is beginning to happen. But the people we spoke to find they are often not supported by larger organisations that could help them with funding and other resources, and Black service users/survivors who are working hard to raise awareness often end up feeling unheard, unvalued and exhausted.

Should Black groups organise separately or be part of a larger movement?

There are differing views on this. Probably because of the experiences with the generic user movement described previously, a number of Black service users/survivors have begun voting with their feet and setting up separate groups. However, many of the people we spoke to are concerned that a Black movement should work alongside the wider movement so that Black issues do not get marginalised.

Factors in favour of a Black movement

Self-help, solidarity and support

Sharing concerns and successes, and learning from each other is seen to be important:

> *'If [Black service user/survivor group] wasn't there, I don't know where I'd be today but it was there, and it has pulled me through. It's just the whole team effort isn't it? Knowing that there's help out there and just getting the right information. I think I'd have been in prison, that's the reality, or the cemetery because I was so bad that time.'*

> *'I think what is good about us is that we don't claim to know. We know what we've been through, we know how it felt and we tell people that and we give people space to tell us what they are, rather than telling them what they are.'*

Support in the community
Black service users/survivors could help to provide mutual support and information within their communities, where there is currently too little availability of social and mental health support, leading to an over-reliance on hospital-based services.

Factors in favour of being part of the wider movement

It makes it easier to get funding, and increases the exchange of information, which enables mutual learning. It also keeps Black issues central, not on the margins:

> *'Minority groups should organise separately but also they should be part of the white movement. We need both. I think in environments where there are white users dominating we will never be able to gain the strength we need to tackle racism. But I would also say don't let the wider user movement hog the limelight. Bang on their doors constantly to let us in.'*

Problems for Black service users/survivors in organising

Ignorance and opposition
Some white service users/survivors do not understand why Black people might want to meet separately, and some are actively opposed to it. Some may insist on telling Black groups what to do and how to do it:

> *'There was resistance from white users to setting up of a Black user group. Some of it wasn't meant as resistance but it was people not really understanding why we want to be separate, and there was a small group of people who were very actively against us setting up a separate group.'*

Finding funding
It may be difficult to get funding, and some Black groups have to accept the offer of a rent-free base in a hospital, which can feel uncomfortable.

Sustaining the effort
It can be hard to sustain efforts if there is no financial and practical support. People become burnt out:

> *'The common element is that we're all tired brains and we're all fighting whether we're white or Black. Some of us have got more to fight than others. I think that all our brains are tired and always stressed.'*

The role of voluntary organisations in relation to Black service users/survivors
Black service users/survivors are concerned that voluntary organisations are run largely by professionals to their own agenda. They may tend to speak on behalf of Black service users/survivors while not demonstrating that they are really listening to them or valuing them. There is a shared perception that some mainstream voluntary sector mental health organisations have failed to connect with people at the grass roots, and are not informed of the good work that Black service users/survivors are doing. There is some resentment that the available funding is going to these organisations and not coming into the communities who need it.

The role of Black professionals in relation to Black service users/survivors

Relationships between Black professionals and Black service users/survivors are different from those among their white counterparts. They are often closer and more supportive, because of common experiences, cultural identities and understandings of religious influence. But just being Black is not enough; Black professionals also need to show empathy with Black service users/survivors. Black professionals sometimes become 'whiter than white', perhaps because of pressures to fit in with their colleagues, and others become ground down and just comply with the system. There are Black professionals who do speak out on mental health issues, but may appear to be talking for Black service users/survivors rather than providing the right environment for them to speak out for themselves. Black service users/survivors may be left feeling patronised, disempowered and let down:

> *'They're causing a lot of harm and actually heightening our disempowerment because they're saying they're speaking for us, and I'm sorry but I'm big enough, and Black enough, to speak for myself.'*
>
> *'I think the movement has moved on in the last few years, but among Afro-Caribbean and Asian people it's been very slow, and I think that's sometimes down to staff. Because there's the feeling of shared experience of discrimination, sometimes they can end up with a different sort of relationship, more informal. One of the problems I've found is that staff are protective of clients where, by giving a lot of support, they're disempowering people a bit, and not sharing information around which might benefit people that use the services.'*

What would Black service users/survivors like to see happening to support their movement?

Recognition

Recognition of the work that Black service users/survivors are doing is one often-repeated issue. It is distressing for people to find their work unrecognised, unacknowledged and unrewarded.

Opportunities to come together

Individuals and groups have created the foundations of a movement, but there is a need for more opportunities to get together, share information and experiences, and create new networks. This has been effective where it has happened. Regular networking meetings would help Black service users/survivors work out what a Black movement should be about, to find its own style and form, rather than following the white-dominated movement or the user involvement model. This would probably mean making links with other Black community organisations, not just those in mental health:

> *'The way forward for the Black survivor movement may be to get involved with other Black movements, more generic Black organisations, because the issues are very common.'*
>
> *'Just imagine, if you've got 400 people inside a room and start saying, "What is our mental health about?", start putting into documents what sort of service we want.'*
>
> *'If you can visualise all these Black and ethnic minority groups, what they stand for, what they have done to date, how they have moved on and they come together with that power, it will be awesome. Maybe other people know that too.'*

More resources to raise awareness

There are suggestions that resources are needed to enable co-ordination and networking. More training, premises to meet and publication of articles to raise awareness would also help. Funding is important, but mutual support is equally important. Black service users/survivors need to be able to come together regularly and share information:

> *'Just having money won't resolve it. It can create as many problems as it can resolve. Therefore, we need to develop our skills, we need to learn how to use resources, we need access to premises and lots of things like that. Just hard cash isn't enough.'*
>
> *'We've got to start creating allies amongst ourselves and maybe there does need to be some funding to allow this, not just once a year or twice a year but maybe every damn month, so we can come together and be allowed to evolve into our own organisation and bring forward the messages that are coming back from our communities.'*
>
> *'Maybe the Sainsbury Centre for Mental Health could facilitate something whereby we could actually be allowed to do something like that, so I hope somebody is actually listening to what we're saying, and that there's going to be some action and some movement.'*

Summary: Black service user/survivor movement

- Black service user/survivor groups exist and Black people are coming together at various events. A Black movement is emerging, and is needed to enable Black service users/survivors to share information and support each other, and to influence Black communities to enable a better understanding of mental health issues.
- At present, groups are small, isolated, poorly funded and largely unrecognised. This leads to stress on the individuals who are trying to sustain them.
- Large voluntary organisations are not doing enough to recognise and support the work of Black service user/survivor groups.
- Black professionals are often allies but can be over-protective and speak on behalf of Black service users/survivors instead of enabling them to speak for themselves.
- The Black movement needs resourcing, not just through money but also through information and practical support, such as providing opportunities for Black service users/survivors to meet together.
- The Black movement may want to work in different ways to the general movement, and may need to link up more with other Black organisations than with the service user/survivor movement.
- Ultimately, Black service users/survivors do want to work alongside and link with the general service user/survivor movement, in order to ensure their concerns are seen as central, not marginalised. They need to organise separately in order to be able to do this from a position of strength.

6

Working together

Service users/survivors working together for shared issues

We have explored some of the problems the movement has in representing such a diverse range of people with different experiences and backgrounds. However, we did find that there are a number of issues that are common to most service users/survivors. Despite our diversity, we can and should work together towards our common aims:

> *'Some of the most effective movements are the ones where you do have a huge diversity but you are prepared to come together for specific issues. So you are going to have arguments among yourselves but you can still say, "We'll have a campaign on this".'*

Ironically, one of the most important things we agree on as a movement is our right to be individuals and to have different needs. We see the biomedical model of mental health as trying to force us to fit into categories that don't match our individual characteristics:

> *'We should always look at the individual – that's paramount … different characters, personalities, backgrounds and not just class them as a user.'*

Our most common concerns are:

- services: improving quality and providing choice, early supportive intervention and alternatives to medical treatments;
- rights and advocacy: no extension to compulsion and a right to independent advocacy;
- recovery and inclusion: elimination of the stigma associated with mental illness diagnoses (e.g. fear of dangerousness) and discrimination.

Services

One thing many respondents agree on is that mental health services need substantial improvement. Nobody we spoke to said that they thought services were fine as they are. While there are examples of good services, especially in the community, the predominance of the biomedical model causes dissatisfaction:

> *'There are some good bits that some people seem fairly happy with. I think there is an enormous problem, in that services are so amazingly medical.'*

Aspects of services that service users/survivors want to change include: staff attitudes, acute services and treatments such as medication and ECT. They want to see more help to prevent people needing hospital treatment and more alternatives to medical treatments:

> *'We often claim to have the same aims as the Department of Health but their objectives are very different. We all claim we want better health services but what we see as better health services is different.'*

Staff

Attitudes of staff to service users/survivors are criticised and respondents want staff to understand them better:

> *'Most of the people I've come across, whether they're white or Black, women or men, tend to think the professionals haven't treated them very well. A support worker coming in every day would probably have done wonders, rather than just a social worker who visits every two or three weeks.'*
>
> *'The staff on the wards could have probably been crying on September 11th, and they wouldn't have got jabbed. If you were a mental health person crying on the ward, you would. But to me it was like, "Well it's only natural to cry"; there were probably thousands of people, millions, doing the same.'*

Acute services

Acute services are often people's first experience of psychiatry and cause particular concern. Women do not feel safe, and many people find their treatment makes them feel worse instead of better. The reforms that have led to acute units attached to general hospitals have not necessarily improved the services provided:

> *'I think acute wards are the pits because the treatment you are given actually makes you worse. In 1999, I ended up on ten different drugs.'*
>
> *'I don't think there should be big units attached to district hospitals. They are awful places. The old hospitals were awful but at least they had gardens and provided some kind of sanctuary. One unit I went to recently was right by the red light district, and didn't have a shop on site, so that the women were going out to buy cigarettes and being propositioned.'*
>
> *'Often I'll go on to a ward and notice six or seven women sitting together and get talking to them and they'll say, "We don't feel safe". It can't be right that people are going into care and then don't feel safe.'*

One way to improve acute services might be to ensure that people's choices of treatment are respected. Crisis cards (cards that say how the holder wants to be treated in a crisis) have been in use among service users/survivors for many years now, and recently some organisations have worked to develop advance directives and negotiate for them to be recognised:

> *'I would not want to see compulsory treatment unless a service user has an advance directive, a clearly defined directive as to under what circumstances they would be prepared to accept compulsory treatment. For instance, if an individual knows that, if they go through extreme periods of sleep deprivation and completely lose it, the directive could state what they really need at that time.'*
>
> *'There is a lot we can do with advance directives, even if we can't change the law – getting agreements locally and establishing it as good practice.'*

Medication and ECT

Treatments are another key area where respondents want to see changes. They want doctors to be aware that drugs are not the answer to life problems. Some respondents call for more control over medical treatments:

> *'GPs just seem to go on prescribing drugs ad infinitum.'*
>
> *'If somebody goes to the doctor and they're depressed they get Prozac. I think if somebody is depressed then there's got to be a reason, so I think instead of shoving them full of tablets and just sending them off again, if you sat down and discussed with the person what's going on in their life, then things would be a lot better. I think tablets can make the situation worse, because you get the tablets, you go home and it doesn't take the problems away that are making you depressed, it's not solving anything, so it's just delaying things.'*

> *'I would like to see ECT banned but, if they wouldn't do that, then it should be a treatment of last resort, with tighter guidelines. They could have approved centres that did it. It would soon stop psychiatrists using it ad hoc if they had to transfer the patient somewhere else. They'd have to ECR* [extra-contractually refer] *them so they'd lose some money as well. I know that sounds cynical but it does make a difference. They would only use it if there was nothing else working in their own service.'*

Supportive intervention in crisis and beyond

Many respondents are interested in how people can be prevented from having to use mental health services in the first place, or how they can avoid needing them on a long-term basis. They want the help offered to be sensitive to each person's particular needs and to build on coping strategies:

> *'I know from my own experience that I don't need to get into quite such a mess if I can be with certain people or have certain things going on for me. People should listen to what people want. For some it is a quiet space but others need to be with people. We shouldn't assume what works for one person works for everybody.'*

> *'It would have been nice to have had better services, more appropriate to my needs, and I certainly didn't need the amount of drugs they dish out. There needs to be asylum, where you can escape somewhere quiet and just take time out.'*

Local healthy living centres or safe houses run by service users/survivors are options some respondents favour:

> *'There was some talk a few years ago locally of developing healthy living centres and I really liked that idea, but nothing's come of it. The idea was to take the focus away from hospitals. A healthy living centre would have different parts to it, for example if you had a back ache and needed some alternative therapies you would go into one part, if you had depression, some kind of mental distress, you would go into another part, so it would be like a generic GP service but separated.'*

> *'I'm really interested in user-led crisis services. I'm not sure whether users should be running them completely because that's quite a heavy thing to do but I think users should be managing them in the sense of deciding what kind of services they should be, what direction they should take.'*

However, as the following quote indicates, there are different views on the level of medical involvement service users/survivors want in a crisis:

> *'Some people want a very independent crisis house, staffed by other service users, that's just a safe place for us to be, and other people want there to be nurses and doctors because that's what makes them feel safe.'*

Self-help and mutual support is a key element for many of the groups we contacted for this research, and they see it as helping people avoid hospital:

> *'I believe in self-help – drawing out people's abilities, building up their confidence again.'*

> *'Letting people know you have been through the same kind of experiences, and they're not alone and have got somebody to talk to.'*

> *'It helps when you meet people who have been inpatients and now they're getting on with their lives.'*

Complementary and alternative therapies are the treatments of choice for some respondents:

> *'I'd love to see a place with plenty of complementary therapies on tap, attention to people's spiritual needs, but not religious in an evangelical sense, a peaceful place where people could come for solace and companionship and finding ways other than drugs.'*

Rights and advocacy

Compulsion in the community

The government has put forward plans to extend compulsory treatment beyond what is allowed under the Mental Health Act 1983, but this is generally opposed on the grounds that it will lead to more oppressive services and worsen relationships between professionals and service users, and it should not be necessary if the right services are in place:

> *'In the community, how do you know when someone has taken their tablets? The worry is that they will give injections instead, and the injections have got more side effects than the newer medications.'*
>
> *'Professionals should be building trusting relationships with their clients but this could be called into question if they are going to have some sort of power over the service user. It could change the nature of the relationship.'*
>
> *'People are going to run away from what there is if they think they are going to get a community treatment order.'*
>
> *'I don't think there would ever be a need for compulsion if services were good. If they were designed to improve people's quality of life and level of well-being people would ask for help, but instead they get intimidation and fear.'*

One respondent wondered whether, for a small minority of service users, compulsory intervention rather than letting them mess up their lives could help preserve their recovery:

> *'I've known a couple of people, brilliant people and they get on really well in the community and everything, but there are times when they really get out of control. I've known people say, "I've really fucked up this time. I've lost my girlfriend and baby. I've lost my job because I told them all to eff off and I smashed a window, and I've really fucked it up for myself." Then they've had to be sectioned or they have gone before the criminal courts, and sometimes I've thought with people like that it might be helpful if there was someone saying, "We know that you're going downhill now, if you're not going to accept the treatment maybe we'll have to give you treatment, enforce it".'*

However, even this person doubted whether it would be the right solution in practice:

> *'If there was any chance that, for a small minority of people, it would actually allow them to be out in the community when otherwise they would be locked up, then I think it would be worth looking into. But I know that most professionals and a lot of users are against it, so I don't know if it's workable.'*

Independent advocacy

Perhaps belief in the right to independent advocacy is the issue that most unites the movement:

> *'I think the right to advocacy is essential and should be enshrined in the legislation.'*

But it needs to be properly funded:

> *'There's one person running it practically single-handedly in this area.'*
>
> *'If it is going to be made a right without increasing funding, they will have to do the legal stuff and won't be able to do the rest.'*

What also comes through strongly is a belief that advocacy should be independent and controlled by users:

> *'You might get a nurse saying she is acting as an advocate but she's not, she's not independent.'*
>
> *'PALS* [Patient Advice and Liaison Service] *and MIND are not independent.'*

> *'I think there's a battle to be fought about whether advocacy is going to be controlled by service users or by steering groups made up of voluntary and professional organisations with perhaps one or two service users on them.'*

Recovery and inclusion

The need to dispel fear and ignorance about mental health issues is mentioned by most respondents. We are united in wanting an end to stigma and discrimination that prevent us from being full members of society. Most respondents wanted to change the perceptions of both professionals and the general public:

> *'Quite a few people can be against the mentally ill – they're frightened of it, basically.'*
>
> *'You can still be refused employment if you have to admit that you're mentally ill.'*

It is hard for people to recover and again become full members of society so long as stigma persists. Public education is the key to many of the changes we want to see in our situation, and the media are a key target for this:

> *'Day-to-day representations of us justify people saying, "They're not the kind of people who can have rights, it's not discrimination, it's because they're ill and because they're dangerous", so I would say that there should be a lot more media work to undo those routine representations about people not being responsible, not being in charge of their own behaviour, before you can start talking about a rights lobby.'*

The chance to live a fulfilling life whether or not mental health problems persist is a concern raised by a number of respondents:

> *'Imagine everyone having a common goal of getting better, whatever that may mean, and finding a way that works.'*
>
> *'We're trying to show a positive side, that people do want to recover, they can recover.'*
>
> *'We think that family is an important part of recovery and the most important thing about your recovery is maintaining that relationship. Working with families I think is something that mental health services aren't good at doing.'*

Summary of shared issues

- Although service users/survivors are a diverse group, we did find there are important shared issues. One of these is the right to be an individual and have services that fit the person, not the label.
- Services need to change; in particular, staff need to be more empathic and supportive. Acute services should be drastically improved, perhaps with the help of advance directives. Doctors should address life issues, not automatically prescribe medication. ECT should be banned or at least more strictly regulated. There should be more emphasis on prevention and non-medical alternatives such as healthy living centres or safe houses should be available at an early stage.
- There is strong opposition to widening compulsory treatment to the community. This would alienate service users and worsen relationships with professionals.
- Independent, well-funded advocacy must be a right for all.
- Recovery, social inclusion and a return to employment will be significantly helped by eliminating stigma and ignorance about mental health issues, including professional misunderstandings. The media promote negative images and this must be addressed. One important aspect of recovery is better support to families to preserve good relationships with service users/survivors.

7

Debating our differences

There are a number of topics that arouse strong reactions among service users/survivors and can lead to splits among us. It is healthy to open up these discussions and look at the range of views that exist and the room there may be for compromise or at least mutual understanding. Among these topics are: forced treatment in hospital, the biomedical model, drug companies funding user groups, closer links with the disabled people's movement, and how far the movement should work with the Government and professional groups.

Forced treatment and detention

Compulsory, or forced treatment, can legally be administered to people detained in hospital under certain sections of the Mental Health Act 1983. This issue has always caused controversy, with some service users/survivors arguing that forcible treatment is a violation of human rights and that services can never become user-centred so long as compulsory treatment exists:

> *'What do they mean by a caring service when you can be told to sit on the bed and shut up and be forcibly injected?'*

We cannot claim that the movement is united in our views on forced treatment. In the United States, this has long been an issue which splits the movement, but here we have usually been willing to work together despite differences on this important ethical issue. However, the movement needs to have the opportunity to discuss the pros and cons of forced treatment and the grounds for detention. Some respondents think compulsion would be unnecessary if services were more responsive to people's needs:

> *'We know that most tragedies have been because of the failure of services to be supplied when people have been asking for them. Where is compulsion here helpful? I just don't think a case is made for it, and I think it's ethically unacceptable.'*
>
> *'If services were more reactive to people's needs, or more proactive in meeting people's needs, then maybe the use of the Mental Health Act wouldn't be as needed. Talking to mental health teams now, they're saying, "We're a crisis service". They used to be much more accessible for people in the community, and encouraged people to contact them. Because of the weight of numbers that are getting referred, they almost discourage them now.'*
>
> *'It's about the betterment of services so that people would actually not think twice about picking up the phone and saying to a CPN or a psychiatrist, "I am feeling ill, I'd like to come in". So before they think about compulsory treatment they should think about the attitude of staff, and alternatives to drugs and ECT.'*

But others see compulsion as necessary sometimes:

> *'I do believe in compulsory treatment. I've been in a position of needing it.'*

Some made a distinction between compulsory detention and forced treatment, accepting that people sometimes need to be detained but not that they should be forced to receive treatment:

> *'I don't think those two words "compulsion" and "treatment" can be put together without there being serious problems. We know that there's a lot of really effective, practical and philosophically worked out stuff coming from survivors about ways of dealing with things which may go wrong, so that they can, without any compulsion, get the right support in place.'*

> *'I think that detaining somebody should be entirely different from medicating somebody, it's almost synonymous at the moment, and I think they should be miles apart, so you have certain safeguards around detention and advance directives which are quite clear. When you actually treat somebody, poison somebody, whatever, against their will, I think it should have a huge amount of safeguards attached to it, not just some poxy second-opinion doctor that comes and looks at you for two minutes. I'm thinking about the blokes I worked with. Whenever they went back in, they instantly got injected, they were quite violent, so they never found out what was the trigger that made them go crazy, so there was no therapeutic input into detention at all, you just got injected. I think compulsory medication prevents you getting better. It's one of the main factors that provokes the revolving door thing, because you never actually stop the cycle, because you never actually find out what the cycle's about.'*

Others were concerned with how society can be protected from people who commit violent acts, without necessarily associating repeated violence with mental illness. To take away personal freedom simply because of a diagnosis of mental illness can be seen as discrimination:

> *'If people have committed a crime and may then commit a similar crime and put other people's rights at risk, I think that people need to be safeguarded. What that might mean it just depends, but I would divorce it from issues of distress and madness because this is not about our states of mind, this is about criminal acts which are most often committed by people where no association with distress or madness is made.'*

> *'We're the only group of people that you can lock away without having done anything. The only other people who get locked away are criminals, people who have actually hurt people and stolen things. Imagine if it was people in wheelchairs or some other group we were talking about.'*

The biomedical model

The justification for forced treatment and detention is based on medical diagnosis of mental illness and dangerousness. But many service users/survivors dispute the very basis for diagnosis, the 'medical model', or more accurately the 'biomedical model' of mental illness. This is another area where there is a wide range of views. For some people, even the idea of disagreeing with doctors can be daunting, especially when they know they will need help again during times of severe problems:

> *'There are people who feel the current services are OK and are very frightened about losing the few services they have.'*

Some suggest that those who are uncritical of the biomedical model may have been indoctrinated with a medical perspective on their problems and may not have had the opportunity to develop a different view:

> *'Many people only know the models that are handed down to them from the system, and they internalise and accept it – "I am a schizophrenic".'*

But one respondent described feeling pressure from critics of the biomedical model within the movement not to admit to depending on psychiatric services:

> *'I use the services, not happily but I use services to keep me alive basically and you're not meant to say that.'*

The challenge of working together despite our differences is summarised in the following:

> *'Some people don't believe in mental illness and some people do. Some people only believe in a kind of political solution to mental health problems, rather than a social or medical solution. Some people see the mental health system as part of a state-controlled attempt to police them. So, when it comes to things like whether hospitals exist or whether physical treatments should be allowed, it is difficult for people to work together.'*

Some respondents wanted to distinguish between the service user movement and the survivor movement, in terms of their relation to the biomedical model, with survivors being more willing to challenge the supposed scientific basis of mental health services:

> *'I think the user movement is about improving services and the survivor movement is about wanting something very different.'*

Those who are critical of the biomedical model seek some basic philosophical shift in thinking about mental health backed up by different practical solutions, based on listening to service users/survivors. One respondent argues that stigma cannot be eliminated without changing the underlying thinking about mental health:

> *'Well I've heard it said that we should accept "mental illness" but not allow it to be stigmatised in any way, which clearly is a barrier for people like myself who want to challenge this view that it actually is an illness.'*

Another thinks the biomedical model makes it hard for services to work humanely:

> *'People need genuine relationships, genuinely being touched and being able to touch others, and a medical model is just the opposite of that, so we need a radical change in changing the mental health professional.'*

Solutions offered include adopting the social model and rights-based work developed by the disabled people's movement, with Direct Payments (payments made directly to the service user enabling them to purchase the help and support they need) helping to establish individual choice as the basis of services:

> *'I think we need to have the equivalent of a fundamental philosophy to shape where we go, like the disabled people's movement has, and we need to reject the mental illness model of distress and madness, and we haven't done that as a movement yet.'*
>
> *'We are still very much into the psychiatric medical model, and how much there are opportunities to move beyond that, I'm not so sure. Hopefully this work we're doing around Direct Payments will move people away from the "you need medication, you need a doctor" kind of thing, focusing on more interesting forms of support that aren't dominated by the diagnosis/illness sort of thing.'*
>
> *'I'd like to see mental health being part of the Department of Work and Pensions more than part of the Department of Health, and I think, while we have employment and everything else led by Health, we're always dragged back into this kind of illness and inadequacy model, rather than a rights and access model. We need to look at what the broad disabled people's movement have achieved by not just rejecting medicalisation but rejecting the whole health construction, I think we've got a lot to learn.'*

One respondent suggests that the issue is not so much one of replacing one model with another as of shifting power towards service users/survivors, and sees opportunities for this in some current debates:

> *'I do think that the post-psychiatry, critical psychiatry movement and the review of the Mental Health Act are two positive things that open up the argument, much more than what anti-psychiatry ever could because anti-psychiatry was about replacing one model with another. Post-psychiatry, critical psychiatry is about saying, "Let's put the views of users and survivors centre stage, let's not privilege any set of ideas above the other", that to me is a real opportunity.'*

Relationship with the disabled people's movement

The debate on the biomedical model cites the need to look at the achievements of the disabled people's movement. It is becoming clear that there are shared concerns for users of mental health services and users of other health and social services. The debates around the drafting and passing of the Disability Discrimination Act 1995 brought some service user/survivor groups into closer alliance with organisations of disabled people in the UK. Some have argued that our interests are so intertwined that the movement should become part of the disabled people's movement. We asked everyone their views on whether we should work more closely with the disabled people's movement (see Table 5).

Table 5 – Closer working with the disabled people's movement

	Should the service user/survivor movement work more closely with the disability movement?			
	Mailing list members	Group officers	National figures	Totals
Yes	8	13	11	32
No	3	3	3	9
Depends on circumstances	6	6	11	23
Totals	17	22	25	64

As Table 5 shows, there is a strong positive response to the idea of closer working with the disabled people's movement, with only one in seven respondents being opposed to it.

Most of those who oppose closer working do so on the grounds that the movement has more urgent things to do, or that nobody in their group has shown an interest in it:

> *'Although there are probably very common goals, I think there's enough to focus on within mental health itself.'*

> *'I know some people think we should and some people think we shouldn't, there's never been any impetus locally on behalf of the users to do that.'*

Some feel that the disabled people's movement is not aware of or sympathetic to mental health issues:

> *'I'm not 100% clear that the disabled people's movement sees mental health service users as part of their constituency.'*

Some have strong reservations because they are unsure about accepting the idea of 'disability' to describe mental health problems. A number of respondents talked about whether people with mental health problems should or should not be defined as disabled. Some think they should, though with reservations:

> *'I certainly experienced it as a disability, an enormous disability, but I can also imagine there are people who would find that very hard, the association would be emotionally difficult for them. So maybe we need another word other than disability?'*

Others think 'disabled' implies a long-term and unchangeable condition. We have included the following quote, though it may be offensive to disabled people, to show the confusion that exists in many respondents' minds about the meaning of the term:

> *'For me a disabled person is somebody that can't do things that they would normally do for their self and that's always going to be like that, but with mental health it's not always going to be such a big problem, I mean it doesn't just go away but I do think that you can work through it, so you can have*

> *as much a normal life as possible once you've worked through the issues that are making you ill, and so I don't think people who have mental health problems should be classed as disabled because they're not, they've just got problems really.'*

Many service users/survivors are aware, however, of the social model of disability, which focuses on the disabling effects of society rather than the person's problems or impairments:

> *'When you work with the social model of disability, however loosely, I think it makes it quite possible for us all to work together.'*

> *'I get increasingly attracted to the term psychiatric disability. You are disabled by psychiatric services, and I think the social model of disability is a useful one, but we need a way of defining ourselves in a way that doesn't just define us as relative to a service.'*

Again, here, reservation is expressed that the disability label does not fully express the complexities of self-definition for mental health service users/survivors.

While aware of the resistance people might feel to having another stigmatising label, 'disabled', with perhaps a worrying sense of permanence attached to it, there is a sense that attitudes are changing:

> *'There are still of course people that are survivors who don't want yet more crap put on them, don't want to be lumped together and having some kind of like impairment or disability in a negative medical sense, but I think in the last few years and I know other people say it, that there's been a much more greater preparedness both amongst survivors and other disabled people to join forces.'*

Some had been influenced in favour by the fact that they themselves or others they knew had both physical and mental health problems:

> *'Being disabled and mentally ill, I think it would be helpful if they worked more together.'*

Among those who are most positive about closer working, a number saw this as an opportunity to move to a more rights-based agenda, particularly around Direct Payments. They feel there is much to learn from the disabled people's movement:

> *'We would have a much louder voice around issues like disability benefits, like Direct Payments. We could learn a lot from the disabled people's movement, because it has done a lot of campaigning around independent living. It was the disabled people's movement that created Direct Payments. The opportunities are huge but it's not happening, because most mental health service users don't even know Direct Payments exist and apply to them. For me that's an example of a missed opportunity.'*

However, a number of respondents cautioned that the movement must keep a separate identity and not simply be absorbed into the disabled people's movement:

> *'We should work on common issues, but I don't think we should just be part of the disabled people's movement.'*

> *'I feel we have a very long tradition and that it's important to build on that, so I would say we need the link but we also need to remain separate.'*

Drug company funding

Pharmaceutical companies have for some years now been offering money to service user/survivor groups. Given the strong views some people hold about the role of psychiatric medication, we asked respondents what they think about service user/survivor groups accepting money from them.

Table 6 shows the figures for each of the three possible views: yes, no and depending on circumstances.

Table 6 – Funding from pharmaceutical companies

	Do you think it is acceptable to receive funding from pharmaceutical companies?			
	Mailing list members	Group officers	National figures	Total
Yes	5	3	2	10
No	4	10	14	28
Depends on circumstances	6	9	7	22
Totals	15	22	23	60

Table 6 shows that opinions are divided, with almost half adamantly opposed and only a small number who have no qualms about accepting money. However, a high proportion say that their decision would depend on the circumstances, which shows the need for more discussion within the movement to work out ethical guidelines.

The figures do not fully reflect the subtleties of this debate, however. Even some of those most adamant that they would never under any circumstances accept money from drug companies can understand why others might decide differently, while those who would accept drug company money often justify this by saying that drug companies make a lot of money from service users and owe them something in return. Those who say it would depend on circumstances range from those who would be very cautious in accepting any money, to those who are willing to consider it with some reservations. Some respondents consider it to be a personal ethical decision rather than an issue on which the movement should have a firm policy.

Yes, I would accept money from drug companies

Drug companies profit from service users and should put something back:

> *'Drug companies are incredibly rich and powerful, and maybe they should give a bit back by funding things. There's loads of people who have got lots of ideas and/or are just waiting to go and do things, but the funding lets them down and you have to shake a tin in the street or something before you actually get something done. So I think these wealthy companies that produce the drugs that we as clients or patients or whatever are taking should give a bit back to us somehow.'*

Service user groups need the money and should accept it:

> *'Yes, why not? I have no moral qualms about taking money from them if it means we can do useful work with it.'*

It's a personal ethical decision and those who are in favour should not be attacked for it:

> *'I don't have any problem working with the pharmaceutical industry. Some people won't talk to me because I work with the pharmaceutical industry and I find that pretty pathetic really. I've never attacked people because they won't work with them so I don't see why I should be attacked because I will work with them.'*

No, I would not under any circumstances accept money from drug companies

Drug companies are immoral and their products damaging:

> *'It's like taking money from the devil.'*

> *'There's a lot of history of damaging effects, for example, paralysis from neuroleptic drugs. The drug companies are in a far more powerful position to defend their drugs than we are to challenge them. Clearly somebody like myself who doesn't accept the notion of chemical imbalances in the brain*

> *actually sees the notion itself as being very damaging and abusive to people. To accept money would be to give legitimacy to the drug companies' view on chemical imbalances, so I wouldn't find it acceptable.'*

Service user groups should avoid taking funding as it will compromise them:

> *'They can't possibly be objective about anything when they are being funded by a major drug company. Nobody could … drug companies are not going to want to talk about alternative therapies, are they? They want to be involved so they can put their side of the argument forward and make it sound as attractive as possible … and possibly even to try and discredit alternative methods.'*

Some opponents feel that the decision not to take money from drug companies is one of personal ethics:

> *'My gut reaction is no way, but I know there is also a view that says they make enough money out of users therefore why shouldn't we get some money back from them, but personally that would really stick in my throat.'*

> *'It doesn't seem right to me but I think it's a personal decision and I wouldn't want it to be a matter of policy for the survivor movement. If there were a debate on whether the survivor movement should or shouldn't take drug company money then I would be against it, but I wouldn't be in favour of it saying no individual should, that's a matter of choice.'*

It depends on the circumstances

Only if the drug company made its position clear and this is found to be acceptable:

> *'I would want to be very clear about what the drug companies wanted from the arrangement. It is not ideal, but it may be OK.'*

> *'I would make sure that they're upfront, all their cards on the table and put it in writing, and then I might agree or might not agree, but at the end of the day the contract is that we would still campaign against your drugs, for our individual clients.'*

Only if the group is desperate for money for a particular good purpose:

> *'We're comfortable now. We don't need to go down that route but if you're desperate then why not? If you need money to develop your people in your group, it might be quite tempting.'*

> *'I'm knee deep in making these bloody funding applications. There's one on behalf of a refugee user group, and I think if somebody said, "Look here's twenty grand", for that group and it's from a drug company I think I'd take it, because it could do a lot of good. I don't know really. These questions are not simple.'*

Only if the drug company is committed to ethical research:

> *'If I knew of a pharmaceutical company that was looking into the effects of anti-psychotic medication, then I would know that they were quite a responsible company, and if they were prepared to offer us some money we might, as I say, but if they've got no history of being aware of what their drugs are doing to people then I think not.'*

Is the movement losing its independence?

Some respondents argue that the movement has lost its independence and radicalism since the development of service user involvement. We asked interviewees their views on this.

There is general agreement that the movement has changed in two major ways:

- Service users and survivors are working more with professionals to reform services.
- There are many more local groups but national groups are less strong.

Working more with service providers to reform services

There are differing opinions about how desirable this is. Some respondents feel the movement has lost its way:

> *'The movement was quite young, was starting to get organised in the mid 1980s, was starting to think about its ideology and direction and then suddenly BANG – service user involvement came along, doors were opened, people were invited in and it was difficult not to get drawn into things that service providers wanted service users to get involved in.'*

But others think it has progressed:

> *'I think it's good. They're becoming more sophisticated. My experience of service users and carers is that when they first get involved they're terribly angry and they have to get this anger out of their system, but when they move on they can actually be constructive in what they are doing, so I think they're becoming more sophisticated now rather than just shouting from the rooftops.'*

A key issue here is whether working closely with service providers and the Department of Health is the most effective way forward or amounts to selling out. Here are two contrasting views:

> *'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.'*

> *'What governments like is a nice easy survivor movement to deal with where they have one or two people they know they can be nice to, they can butter up, they can invite to soirées and get on board, and I think that's very bad for the survivors' movement. Survivor involvement is always a dangerous balance between wanting to get access to and influence people without being seduced by the whole process.'*

Some respondents take a more neutral position:

> *'If the health service is paying your wages you are going to have to work to their agenda to some degree. It's got pluses and minuses. If people are giving you money they're taking you seriously, so obviously they want to work with you and that's good. But it depends on how constraining those kinds of links are. Some people are very controlling and others are very flexible and see the need for service users to challenge the services, and actually have an interest in seeing that happen.'*

There are many more local groups but national groups are less strong

Some feel the movement is less cohesive:

> *'I don't have the sense of there being a collective movement which we had in the late 1980s and early 1990s when Survivors Speak Out, Mindlink and UKAN were significant national organisations and there was a degree of collaboration between them. I think the opportunities for people to be involved in consultation, training, research or even jobs pulled people away from the actual organisation. And there were significant problems with funding and also meeting the kind of demands there were on organisations such as whether you should be a charity or not, your accounts. These sorts of things certainly undermined Survivors Speak Out.'*

Another isn't so sure that there ever has been a strong national movement:

> *'I've thought a lot about the survivors' movement in relation to the movement of disabled people. We've always had difficulties unifying at a national level. We have got a number of different organisations. We haven't had the clear-cut independent organisational leadership that some other movements have got. But what I do feel we have are loads of flourishing local groups and, for me, that's the strength of the survivors' movement.'*

And, finally, a view that the movement, as it currently exists, provides a place for everybody:

> *'I think that the more people you get involved in the service user movement the less radical it's going to be, because to start with it's the more radical people who come together. Now we've got a much wider movement. People aren't necessarily radical in their perspectives and that's fine as long as people are saying what they want to say. But I think there's still room for radicals in the movement. I think organisations like the Hearing Voices movement are radical because they are saying hearing voices isn't a symptom of an illness at all, and Mad Pride which is about reclaiming the right to be mad and proud, and there's elements of people talking about different models of mental health. So there are still a lot of radical elements but you can't expect everyone to subscribe to those agendas.'*

Summary of debating our differences

- We selected some important issues of controversy and looked at the range of views that exist around these. This is a start towards establishing a national discussion on these topics, which could help us to avoid personalising our differences and understand better why we hold our beliefs and views.
- Forced treatment and detention are seen by some as preventing services ever being truly user-centred and they argue that, if good and responsive services are available, there will be no need for compulsion. Others see compulsion as sometimes necessary. It is argued strongly that detention and forced treatment are two separate issues, and should be treated differently. People need to stop associating violence with a diagnosis of mental illness. While society needs protection, the reasons for violent behaviour need to be explored.
- 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, it may be that we are united on the importance of putting the views of service users/survivors centre stage, and seeking practical solutions that enable choice, such as Direct Payments.
- The majority want a closer relationship with the disabled people's movement, as there are perceived to be many common issues, though 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 us to establish a more rights-based movement. Some fear that too close a link could compromise our independence and want to ensure that the movement retains its own identity.
- The funding of user groups by drug companies has been very divisive to the movement. We found that, while almost half are clearly opposed to this, a high proportion say 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 should give something back. Some think this is an individual ethical decision and not something the movement should dictate. There is a need for the movement to develop ethical guidelines on this issue.
- Has the movement been compromised by closer working with the government and professionals? Does it still have a strong independent identity? Some respondents consider that

user involvement has weakened the movement by substituting government agendas for our own agendas, though others see this as the movement growing up and becoming involved in real change. 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. National groups are not currently strong enough to influence national policy or to keep local groups in touch with each other and aware of belonging to a movement.

8 User involvement

We found that user involvement is one of the main activities carried out by service user/survivor groups. Clearly, what motivates people to become involved is to improve services, which the majority of service users/survivors regard as important. However, many service users/survivors are concerned that too much focus on user involvement can detract from the campaigning and mutual support aspects of the movement. In this chapter, we look at how satisfactory user involvement is from the perspectives of service users/survivors.

We begin by looking at an example of user involvement at a national level, in the consultation on the NSF for Mental Health, which took place between 1997 and 1999. The experiences of service users/survivors who took part in this are described in depth, to show some of the problems that can arise if user involvement is not well thought out. We follow this by comparing people's experiences of user involvement to a set of principles generated by service users/survivors. Finally, we describe our observations of local user involvement in the implementation of the NSF for Mental Health, and discuss the pros and cons of user involvement for the movement.

User involvement in creating the NSF for Mental Health

In 1997, the government commenced work on a framework of national standards for mental health services. The first stage involved setting up a consultative committee, the Independent Reference Group (IRG) of experts in the professional and voluntary mental health sectors. Some service users/survivors were invited to join the IRG. This was expanded in 1998 and renamed the External Reference Group (ERG) to work on developing the NSF for Mental Health. Sub-groups were formed within the ERG and a two-day meeting was held in Stoke during the process. The ERG produced its report in 1999.

This is the most recent example of service users/survivors being involved in a major piece of work at a national level. We interviewed six of the eight service users/survivors who were members of the ERG to find out about their experiences.

Recruiting service users/survivors to the NSF consultation group

There was no strategy for recruiting service users/survivors and people joined through a variety of routes. Some respondents were recruited from national groups after one person had phoned the Department of Health (DoH) to complain that no users were involved. Another joined after she had complained to a voluntary organisation she belonged to that none of its representatives on the ERG were service users/survivors. Another person who joined was from a service user/survivor group that others did not feel was nationally representative. Two Black service users/survivors were invited after they had made a presentation to a DoH group about their experiences of acute wards. Respondents had difficulty in finding out what they were being invited to do:

> *'We kept trying to find out and asking for papers without success. It wasn't until the meetings started that we had a clue of what it was about.'*

The service users/survivors were then allocated to various sub-groups in a way that seemed arbitrary. They were given no choice and the groups they sat on did not necessarily match their interests or expertise. Some found that they were the only service user/survivor in their group. One respondent tried to change the situation but with no success:

> *'The chair of the sub-group tried to be charming but I knew I wasn't being heard. He was using the sort of tactic you read about, "Yes, yes, of course, dear", and very patronising. At each meeting he'd say, "Sorry, I was so busy I forgot".'*

Relationships between service users and professionals on the NSF consultation group

Once on the sub-groups, the service users/survivors experienced a variety of responses from other members who included chief executives of trusts, psychiatrists and other senior professionals, and people from independent and voluntary mental health organisations:

> *'When service users were saying they felt quite uncomfortable and they would like to make sure at least two of them were always together, comments were made such as, "Then why can't we have two psychiatrists, two social workers, and so on?", and we said, "You've got to understand that service users need to support each other", and they said, "Just think yourself lucky that you've got any representation".'*

> *'P was wonderful, she was a lovely person. She really understood what was going on and was trying to stop us getting devoured, I guess. She was very thoughtful around us.'*

An overview of user involvement in producing the NSF

As the work of the ERG progressed, it appeared that user involvement had not been thought through in advance:

> *'When they were talking about service users' voices being heard, they were talking about the Mental Health Foundation and MIND staff being the voice of the service user, which I don't think was accurate.'*

One respondent was pleased to find themselves on the service user and carer outcomes group because it seemed to be the most relevant. But, they ended up feeling sidelined:

> *'We hardly looked at service user and carer outcomes except in a rushed way at the end. Until then we had been looking at things like information systems. It was all from professional perspectives – how the systems could be improved for staff.'*

A meeting in Stoke was a particular trial for some of the service users/survivors. One told of overhearing people saying things like 'They aren't representative, they're too articulate' and 'They obviously haven't been in hospital for years'. But she thinks it must have come to the attention of the chair of the ERG because:

> *'He started off the second day making this public announcement that it had come to his attention that service users were being told they weren't representative. He said that no one there was representative – everyone was as representative as everybody else. I think he said something about race and culture too. They got a bit of a ticking off. It seemed to change things. We started prioritising these standards we had put together and suddenly service user involvement was at the top.'*

But summing up the whole experience, one respondent still said:

> *'It was one of the most disempowering experiences I've ever had in terms of service user involvement.'*

Black and minority ethnic groups in the NSF process

Black and minority ethnic groups, who are particularly disempowered in the mental health system, and have a lot of important things to say, were also recruited in an *ad hoc* way. Professionals who have long been regarded as experts on race, culture and mental health were not invited onto the ERG. This put particular pressure on the Black service users/survivors who found themselves trying to represent two groups (service users generally and minority ethnic people in particular):

> *'I noticed that I was the only one raising issues of minority needs. I felt angry about it because these were people in responsible positions, chief executives and so on, and I found it difficult to understand why they couldn't take this on. I did notice two or three people who started to speak out on these issues but I kept wondering if they would have brought them up if I hadn't. Basically, I felt the institutionalised racism within the services was being played out in the group.'*

Because of their concerns that issues of race and culture were not being taken seriously, some Black professionals wrote a public letter that was published in the press, criticising the lack of involvement of key experts. Unfortunately, this had the effect of making the Black service users/survivors who were involved feel they were being criticised for not doing a good job:

> *'It was more or less saying that we were not experienced. It was helpful in one way because it was saying what needed to be said but it was worded badly.'*

Resigning or sticking it out – difficult choices

Not all the respondents stayed till the end of the process. A Black respondent resigned because she was disillusioned with the way issues of race and culture were being dealt with. Three other respondents resigned following a decision by their organisation:

> *'There was conflict between trying to help put together policy as service users involved with the ERG while knowing that the same, or similar, people at the DoH were putting together this legislation that was going to take away a lot of our civil liberties.'*

So why did the others stay on? One explained:

> *'It was important to be part of the whole process and I am one for working within the system. Resigning didn't make a jot of difference, in my view, and it just demonstrated that we are awkward, difficult, whatever; because everyone involved felt the whole process was terrible and so why resign particularly?'*

Decisions about resigning and not resigning demonstrate the dilemmas of service user involvement, and the differing attitudes and degrees of tolerance of individuals and organisations for working with 'the establishment'. So it is not surprising that one respondent who resigned found:

> *'There was a mixed reaction from other service users. Some thought we should have hung in there and others said, "How could you stay there that long?"'*

Relationships between service users on the NSF consultation group

Relationships were damaged by the muddled attitudes towards user involvement throughout the process. For example, the ways in which people became members of the ERG meant that there were feelings about who did and didn't get involved:

> *'I went to a meeting with the Chair of the ERG to discuss service user representation because people were disappointed about who was being elected on. When it is something as important as that, it should be people from national organisations who could take directives from other service users.'*

At the beginning, it was hard to even find out who else was involved. Eventually, at the Stoke meeting, service users/survivors were able to get together for the first time, but only by setting up a meeting at a time when they were meant to be having a break:

> *'If they'd got any idea about user involvement, they would have planned it in as part of the programme, rather than make us miss our rest time in order to support each other.'*

But, by then, relationships had become strained:

> *'There didn't seem to be any solidarity between service users there at all, in fact there was a little bit of antagonism. That was quite difficult to manage, sometimes, because you didn't know who you could trust.'*

Some of these difficulties arose because the Black service users/survivors didn't feel that the white service users/survivors fully appreciated the struggle they were having. A white service user/survivor explains how they saw this happen:

> *'The Black service users felt very marginalised. Because I'd been involved in this sort of thing before, I didn't feel marginalised, I thought it was just the same as ever. But what I did conceive and acknowledge was that Black and minority issues hadn't been taken on board.'*

But this is how the situation looked from the perspective of a Black service user/survivor:

> *'When the survivors did get together at Stoke, some of the white survivors seemed really uncomfortable and embarrassed when we spoke about racism, and it felt as if they were implying that we didn't know how to play politics and, "Of course, we wouldn't say anything like that".'*

The overall process of producing the NSF

It is clear, from the comments of the respondents that the process of putting the NSF together was hurried and chaotic, and that it was not just service users who were dissatisfied with this process and the outcome. Respondents were often very unclear about what they were supposed to be doing. And it would seem that, after the ERG and the sub-groups had completed their work, many changes were made:

> *'The general feeling about the whole process was that it was an incredibly damaging, horrible thing to be involved in. I think one of the strengths of it was how everybody involved felt awful about it – everyone felt totally betrayed and maligned, not just the service users. But we had a head start in feeling maligned because we hadn't been involved properly from the beginning.'*

And one respondent concluded:

> *'It was deeply, deeply shocking that this is how policy is formulated.'*

The final document – the NSF for Mental Health

The respondents were not pleased with the final document and felt that some of the most important work that had been done was not included:

> *'We came away from Stoke, feeling quite traumatised, but saying, "We've set ten standards and the top one is service user involvement, the second is race and culture; so anything that comes out is going to have these at the top." Of course, when the National Service Framework came out, it said, "Service user involvement is assumed in everything we're talking about" but it wasn't picked out as a specific standard which I think it should have been. That was shocking to me because at Stoke it got more votes than anything else.'*

Final reflections

Each respondent was asked, 'Would you get involved with something like this again?'

Comments ranged from:

> *'No way. I didn't feel particularly traumatised by the experience but I wouldn't do it again because I don't think our voices were heard, and the way the whole race and culture thing was treated just stank.'*

To:

> *'I'd say yes, as long as you pay me. Because I think it is important for service users to be involved but I won't do it without being paid. I would want my voice to have equal weight to everybody else. I don't want to be representative of anybody because it's impossible. You get yourself into a real hole if you try to be representative and you can't be.'*

It was clear that respondents did not want to be put in the same situation again. However, one respondent who declined to be interviewed specifically about the NSF experience commented about it in a general interview for the research. His experience differed from the rest of the group:

> *'I realise this is not a universal view, but I was quite happy with the External Reference Group, I think there were more service users on that reference group than there were clinicians and that wouldn't have happened a few years ago, and I believe that the chair of the ERG made strenuous efforts to make sure that service users were empowered, listened to, to the point that he even gave them their own sub-group, which I felt was good, and I felt part of the group that could choose the National Service Framework. I'd be the first to say that some of my service user colleagues might take a contrary view, but you take things as you find them.'*

A comparison of the NSF consultation with other examples of service user involvement at a national level

So does service user involvement at a national level always have to be this painful? Several respondents compared their experiences on the ERG with other national initiatives they had been involved with. Three had been part of the service user group of the Mental Health Task Force in the early 1990s. All felt it had been a more positive experience:

> *'There were ten of us who just stayed together and we got on with the projects and didn't have too much interference.'*

After the Task Force, there was a National Service User and Carer Group, which was a multi-disability group. Someone who was a member described what happened to it:

> *'The minister in charge of mental health ran it for a long time, and they produced some good stuff. But as soon as a new government came to power they disbanded it. It had taken us four years before we started recognising similarities rather than differences, and started to work to common agendas. It had just started to work and they got rid of it.'*

More recently, the new National Institute for Mental Health in England (NIMHE) has set up a User and Carer Expert Committee and a number of regional user champions have been appointed. Criticisms have again arisen from the movement about the way service users and survivors have been recruited to these functions, suggesting that lessons are not being learned. It is not clear that the movement as a whole is being taken into account when recruiting representatives to high-level consultation bodies. However, it is early days yet, and it may be that lessons will be learned and representation will improve. The task force work of the previous government, though effective in terms of user involvement, was less effective at the implementation stage, and user involvement in NIMHE could potentially have greater impact on service provision.

Summary of lessons from the NSF consultation experience

- Initial recruitment to national bodies should be seen to be done fairly and openly, by inviting representatives from a range of national service user/survivor organisations, and including representatives from Black and minority ethnic service user/survivor organisations even if these are not currently national bodies.
- All recruits (whether or not they are service users/survivors) should be properly inducted into the purposes of the consultation, and the role of service user/survivor representatives should be made clear to all.
- There should be time and resources set aside for service user/survivor representatives to meet together outside the actual meeting (maybe before or after it).
- Service user/survivor representatives should have a reasonable choice as to how their skills can best be utilised in the process.
- Black and minority ethnic interests should be well represented, not just by Black and minority ethnic service users/survivors.
- The results of the consultation should be seen to be effectively utilised in the final piece of work resulting from the consultation.
- Sufficient time and resources should be allowed to ensure that all these points can be taken into account when planning future consultations.

Learning the lessons – moving towards more effective user involvement

The lessons gained from the experience of our respondents who were involved in the NSF consultation can and should be taken on board wherever service users/survivors are being asked to take part in decision making. We have integrated them into a set of principles, which is also derived from a paper co-written by one of the authors of this report (see Box 8).

Box 8 – Draft Principles for User Involvement

1. Make user involvement the norm
There needs to be willingness and acceptance from professionals that service users/survivors have a right to be involved and that this should be automatically built into their ways of working.

2. A base of support and accountability
Users need their own organisations, structures and meetings to give them a base to work from. If there are no local service user organisations then help should be available to build this capacity. Existing service user/survivor organisations should be invited to send representatives to any local, regional or national consultations.

3. Examine and deal with power imbalances
Imbalances of power between users and professionals need to be acknowledged, confronted and overcome.

4. Outreach – going to where the service users/survivors are
Professionals need to be prepared to go to service user/survivor groups (provided that this is wanted by the members) rather than always expecting service user/survivor groups to send representatives to professionals' meetings. There needs to be a constant, well-directed effort to involve people from marginalised groups who may not be keen to come to meetings.

5. Service users/survivors making their own decisions about involvement
Service users/survivors have a right to decide what they want to do (or don't want to do) and should not be expected to fit in with other people's plans for them.

continued

6. Value the expertise of service users/survivors and help them gain new skills and confidence

The existing experience, knowledge and skills of service users/survivors should be valued, even though they may be very different from those of professionals. Service users/survivors may also need opportunities to learn, to broaden their experience, to develop new skills and to build their confidence.

7. Sensitivity about paying service users/survivors

Professionals need to be proactive in ensuring that financial matters are handled fairly and sensitively. This may include giving someone travel expenses in advance or initiating discussion about paying fees for users' contributions.

8. Professionals need training too

Professionals need training in user involvement and understanding service users'/survivors' perspectives.

9. Service users/survivors and carers are not interchangeable

Service users/survivors can feel disempowered by 'carers' and be in conflict with them. They should not be lumped together as one group (although they may choose to work together on issues of common interest).

10. Mental health organisations such as trusts and regional development centres should set up user involvement policies and programmes to implement involvement and act on the outcomes of involvement

User involvement costs money. There should be a budget for it, along with a policy and programme, and someone with responsibility for implementing it. Professionals should invite service users/survivors to get involved only if there is an opportunity to make real changes resulting from their work.

Adapted from a paper by Veronica Dewan and Jim Read (unpublished).

Experiences of user involvement compared to the Draft Principles

In this section, we have taken the lessons from the previous section as encapsulated in Box 8, and then applied them to the experiences of respondents with regard to local and regional user involvement.

Principle 1: make user involvement the norm

Although user involvement may not have become the norm everywhere, we found there are usually some opportunities to get involved.

Opportunities include a wide range of local and regional mental health service planning and decision-making bodies, for instance NSF Local Implementation Group (LIG) meetings, professional selection panels, and involvement on management committees at large and small voluntary sector projects:

> *'Yeah, I think the battle has been won really and I think now that people know that it does make sense to involve users.'*
>
> *'We have lots of influence now and it is growing. The services cannot get away without asking us anymore.'*

Principle 2: a base of support and accountability

Service providers and planners often invite service users/survivors to get involved when they have no base to work from or colleagues to support them. They may do well for a while but, without other people to support them and to be accountable to, they are likely to struggle and become vulnerable to criticism.

Some areas have set up excellent arrangements for people to work together:

> *'We set up a user reference group for all users who work with professionals on a paid basis and that is very effective because people can raise issues. Someone in the room says, "That happens to me, what can we do about it?" I think there should be more things like that, groups where users can share these difficulties of being involved, and the successes and the strategies that seem to work.'*

Creative use of communications technology could help people take part without having to travel to meetings:

> *'I was asked to sit on a committee once but because of my agoraphobia I couldn't go and I said, "Well use a tele-conference then and you'll save a lot of money because people don't have to travel" but there was a reluctance to accept the idea that you can meet on the phone. It could actually save the government and the NHS a hell of a lot of money instead of paying travelling expenses for a two-hour meeting in Manchester as everyone could do it from the comfort of their own home and you don't disenfranchise people.'*

A Black group describe their way of doing user involvement on their own terms, from their own base:

> *'We suggested to them that, if they wanted to hear our views, we would sit here and have a discussion and tape it, because we were having discussions one day and somebody said, "It's so good what we're saying, let's tape it", so we've got a tape on medication. It is stunning, because it's not just, "We hate medication, we want to come off medication". We talked about how when we come in they put us on maximum doses of medication and then we never go off it, so we talked about your doctor making a contract with you when you come in, and in that contract it being agreed that you will be put on this medication for a certain amount of time and then it will reviewed, and the whole detail of the contract came from the discussion, and that's something for a long time we've wanted to put in black and white, so we're doing things on our terms.'*

Principle 3: examine and deal with power imbalances

We found the most common practice in user involvement is for service users to be invited to join existing committees along with professionals. They often feel in an unequal position until they gain enough experience and confidence to speak out. Even then, professionals ultimately carry the power and responsibility to make major decisions. Service users/survivors will be used to professionals having formal and informal authority over them on a personal level. Power imbalances should be acknowledged and dealt with openly, perhaps by creating new power-sharing structures:

> *'I am a little bit worried about all this user representation and user involvement agenda, I cannot believe that it's more than tokenism in a lot of cases, nor can I see the mechanism by which it can be more than that, because of the power relationship, it always relies on the grace and favour of those in power, and I'm not saying people won't listen, always there are some people who do listen, but any right that is dependent on the grace and favour of an oppressor, I am suspicious about.'*

> *'The biggest thing that needs to happen for user involvement to work is mental health professionals being aware of their own power, and being prepared to change the ways they work, not just expecting users to slot into their culture and the way that they do things. This can be anything from an expectation that meetings will start at nine in the morning, to having sufficient breaks, to providing*

> *information in accessible formats, not using lots of jargon. They shouldn't expect people to immediately understand something they [the professionals] could have been working with for a year, because it won't happen and people will continue to be excluded, they will just be a bum on a seat.'*

In some areas, new structures and methods are being developed to give service users/survivors a better chance to make a real impact. One meeting we visited was a project group aiming to develop user involvement in a comprehensive performance assessment (CPA) audit:

> *'The original method of involving users didn't work so the group are now planning an open day. The aim of the open day is quite modest – to make the CPA make sense to people, reduce problems, etc. The material produced by the user representative to advertise the upcoming open day is headed first with the name of the user group, then followed by the name of the NHS trust, this makes it seem like genuine joint working.'*

Principle 4: outreach – going to where the service users/survivors are

Service user/survivor groups often have to lobby to be included rather than professionals making the effort to meet them on their own territory. Venues for meetings that service users/survivors are invited to are usually health service buildings. One Black group officer criticised the lack of opportunities provided for Black people to get involved locally:

> *'There's a lot of stuff going on, the Health Action Zone, primary care groups, everything going on, NSF, and I've not been involved in hardly anything, a lot have no Black people on them.'*

Another Black group officer spoke about the problems of involving the South Asian communities:

> *'I am disappointed at the lack of South Asian involvement because so many opportunities come along which are passed on to users, but close to 80% of them are not interested, they say, "We've come here for support, we get it, thank you very much, you carry on with what you're doing, you're getting paid so good luck to you". One needs to work at it full time, to get more people to understand, they just think, "We have made an appointment, we're referred to you for a service, end of story" and it's not, next year the user project might not exist and where will they go?'*

This group officer is doing his best but, if professionals genuinely want the involvement of groups who have been marginalised, they must share the responsibility for this outreach work with service user/survivor groups:

> *'I think they need to take more of a step towards people with mental health difficulties, rather than it necessarily coming from people who are already disadvantaged both financially and in terms of maybe their confidence.'*

> *'It would be nice to think, "OK the local gay and lesbian mental health group are having a disco tonight and if you really care social services, you come down there and start dancing, then we can see you really care", rather than like, "Why do we all have to go to your offices and let's all be anonymous".'*

One respondent described the contribution that can be made even by people who are currently experiencing severe difficulties:

> *'Users who find themselves involved are often the ones who present as being very well, and I think people who are extremely unwell still can have a say and are able to communicate in their own way, what their opinion is and what their needs are, but that needs time and patience. Sometimes when somebody has been to our meeting and been acutely unwell, quite psychotic, detached from reality, seemingly not taking in any information at all, all of a sudden they'll come out with one thing and I'll think, "That was so good and so important, I would never have heard that if I hadn't given them the chance to come to that meeting".'*

Principle 5: service users/survivors making their own decisions about involvement

Service user/survivor groups do not exist for the sole purpose of providing representatives to take part in service planning. If experience tells them that their views are not being taken seriously, it is reasonable for them to withdraw from involvement and concentrate on activities that are more satisfying and worthwhile. A Black service user/survivor group flooded with invitations to take part in committees has a policy of checking in advance the scope of what is being offered to ensure they do not waste their energy:

> *'You get letters every day, asking you to go to boring meetings but we'd already seen that nothing happens 99% of the time. So, we send a standard letter which says, "Thank you for asking us to sit on your committee, we're interested in the issues and they are important to us as Black users. We would love to come and sit on your committee if you can just reassure us in writing that our presence will make a real difference to Black users." We just get involved with the people that are prepared to put in writing that they're going to take on board our views. So that's a policy we've worked out.'*

Another group have evolved their own way of doing user involvement, which retains their power and choice. They have set themselves up as a consultancy and now get involved only on a paid basis:

> *'We are a limited company, so all the work we do is on a contract. The group has evolved from that kind of democracy where accountability is built in to a social firm where users who want to get involved get a contract and get paid. There are no volunteers. No management group watch from the sidelines. Everyone involved is working on a project. There is too much going on to feed everything back. We share information via an intranet, but the group acts as a support network rather than a management group to be accountable to.'*

Principle 6: value the expertise of service users/survivors and help them gain new skills and confidence

The contribution that service users/survivors bring to decision making is based on personal experience, often enhanced by life and work experiences before and since the mental health problem. These skills may be different from those of mental health professionals but should be respected and valued:

> *'I get the feeling that the professionals are thinking, "Well we're experts, we know what we want to do with the money, so what's the point in talking to them?"'*
>
> *'I think recognising the sort of skills and experience that users are bringing, the expertise and respecting that is important. Also not making assumptions about people, about what they might find stressful or what their experience is.'*

This expertise should be valued by offering payment and good working conditions:

> *'Some organisations give us an amount of money every year for providing representation. A half-day meeting now may be worth £35, a full-day £70. If people go for an hour meeting they might get £10 and taxi expenses. Payment should be mandatory and I think not a tokenistic payment either, a proper payment for people's time. They should have support with travelling, if travelling is difficult for them, that could be taxis or somebody who's willing to drive them there and back from the meetings or travel with them on the bus. Support actually in the meeting, if somebody feels too anxious to actually sit through a meeting on their own, interpreters in case their first language isn't English. Some people may need to take a break every 20 minutes, they should be able to do that.'*

Some people do not have the confidence to get involved without an initial input of support and training. Most of the mailing list members we talked to had done little or no user involvement work. Some said this is because they were not sufficiently 'well' or confident at the time they were asked to take part:

> *'I think one of the most important issues is training service users to be actually effective in what they do. There's a presumption you can pick a patient off of a ward and they then can be involved, but they need a lot of training and support to do it effectively.'*

However, in some areas, people are supported to gain the skills to take part. In one area, a training scheme is funded by the local trust:

> *'The local User Voice scheme provides people with the necessary skills to sit on committees, such as how to make an effective contribution at such meetings and pay a reasonable fee for you to attend these meetings. Overall, that's a nice package to attract people who are both articulate and service users too, and provides for the training of those who are less articulate to become so.'*

In another area, user involvement workers help service users to get access to quality training and experience:

> *'We try and make sure that people have full access to the training that other community groups have in the city, so there's free training available, from issues of assertiveness to committee skills, dealing with difficult people is one that we went onto and we try and make them aware of that, and then we try to get a couple of representatives to major national conferences. And then users have their own budgets which as a group they decide what to spend that on.'*

Principle 7: sensitivity about paying service users/survivors

There are many sensitive issues about service users/survivors being paid for their input. This is especially so if they are receiving benefits or on low incomes, working alongside salaried staff. For example, standard procedures for reimbursing travel costs may be completely inappropriate for people who struggle to find the money in the first place.

A user involvement worker explains the protocol for payment used in the trust where he works:

> *'It's either £10 an hour or £80 a day. There's a protocol attached to that which advises people about whether to seek advice on benefits and whether or not to accept the payment. They can have payment in instalments if that will keep them under their weekly level they are allowed to receive. There's also a paragraph right at the beginning that says that accepting payment doesn't compromise your independence, which I think was important for people that they didn't feel that they were accepting the King's shillings so to speak.'*

A few respondents raise the fear that paying service users/survivors for their involvement could lead to people doing it only for the payment, yet they still think payment is necessary:

> *'I know of at least one person in our area who goes to everything she possibly can, because she knows she gets paid, and doesn't contribute anything! But I think what payment does is encourage people. We have quite a lot of consultation meetings and people who aren't actively involved in any other way will often be encouraged to go along to talk about the services in the knowledge that they're going to get paid £5/10 to do it, so I think it does encourage people who aren't really committed to take that first step.'*

Principle 8: professionals need training too

If user involvement is to succeed, professionals need to understand its value and know what helps to sustain it. They also need to know about the service user/survivor groups in their area and the national organisations. Training may be available from local service user/survivor groups or, if not, from user consultants from other areas. For example, professionals need to learn how to ensure that meetings are accessible to all by avoiding using jargon terms:

> *'I think it's still an issue, there tends to be lots of use of abbreviations, I think that can be quite disempowering because managers who very often go to so many different forums often use these acronyms, but for the rest of us it's hard to keep up. But I've come across a couple of instances where service users have been at a meeting for the first time, where one of the chairs of the meeting has set aside time to bring people up to speed, in a very sort of empowering way, not at all patronising, saying, "This is what I can do now, if you need more information, I can do that".'*

One respondent suggested that professionals need opportunities to get together and clarify their understanding of involving service users/survivors before embarking on it:

> *'I really think that professionals need to have some space on their own away from users to decide if they actually want user involvement, and then how are they best going to work with that? How much commitment are they going to make? Because I think if they're clear in their mind before they start then there's a vague chance that they won't abuse the users that they get involved with.'*

Principle 9: service users/survivors and carers are not interchangeable

Nobody in this study raised as an issue the problem of service users/survivors and carers being seen as interchangeable. While it seems to be common for both service user/survivor and carer representatives to be invited to take part in meetings such as Local Implementation Groups, it appears that it is now generally accepted that the two groups have separate identities and issues. We did not ask any specific questions about this so it may be that some residual problems do exist but were not reported to us. There is, however, still some evidence that major mental health voluntary organisations are sometimes incorrectly seen as able to speak for service users and survivors.

Principle 10: mental health organisations such as trusts and regional development centres should set up user involvement policies and programmes to implement involvement and act on the outcomes of involvement

User involvement cannot happen without a budget to cover the work of outreach to service user/survivor groups and to build their capacity to respond to calls for involvement. Too often, funding comes from under-spent budgets and becomes available only at the last minute. If the reality of user involvement is to match the rhetoric, then funding for service user/survivor groups and the other expenses of user involvement will have to be on a more solid basis:

> *'I think a local Framework document would be very useful because it could be the basis of a timetable and it could say, "In the next three years we're going to resource, for instance, user involvement in care plans, we're going to resource people to sit on interview panels, then you know that the money's going to be there, not just money but the support."'*
>
> *'There should be enough money to pay for the support infrastructure, people need to be trained to take part in meetings, because often it gets quite technical, there needs to be somebody whose sole job it is to support the user forums in every area and support the overall user forum. Then you've got to have money to pay for transport, not everybody can drive, even if you pay their petrol they probably can't get there from the rural areas. You need to make sure that you've also got the support in each of the local areas, it's not enough to have somebody countywide to do it. So I think we're talking about at least 15–20 hours a week in each locality and a full-time countywide co-ordinator, plus a budget for user payments to meetings, plus a user trainer and transport. This is not peanuts we're talking and, if you don't have that, you have a lot of goodwill at first and then people won't turn up to meetings, they'll get demoralised, they'll get overwhelmed and things will just fall apart, and then professionals will get fed up and say user involvement doesn't work, but it does, it's just providing the backing.'*

Funding for user involvement should be part of a well thought out strategic framework. Regional centres and local authorities need user involvement policies based on what has been shown to work and on learning from experience. If user involvement is poorly done because of a lack of structure and clarity, the resulting cynicism generated among service users/survivors can set the process back by years:

> *'There are a lot of people who wouldn't get involved again. What seems to have happened is that it comes in phases so people go in, they get disillusioned, they move away and then a whole load of new users go in and get disillusioned, then there's the few who hang in there. But I don't think the set up is there to learn. Using the National Service Framework as an example, users were involved on that, almost every user on that had a bad experience and what have the Department of Health learnt from that? They've never been back to any of us to ask us the feedback on that process. What's the point if they're not learning from their experience, unless they think they're so perfect that they've got nothing to learn!'*

Some respondents suggest that local user involvement policies and programmes should be based on the guidance in the NSF, to provide a baseline, adapted to take into account the different needs and cultures of each locality. A plan could be set out and then discussed with local service users/survivors so that everyone knows what is to be achieved in the next few years. The plan would include the offer of resources, support and training to local service users/survivors, without affecting the independence of the service user/survivor groups.

In one area, a user involvement strategy has been designed by the local user forum:

> *'They've accepted for the whole new trust the user involvement strategy that we wrote, the local user forum, everybody together, and that includes everything from training, audit, interviewing, recruitment, planning, development, the whole lot including payments and everything.'*

Finally, service users/survivors need to see that the results of user involvement are being implemented. If user involvement is merely a tick-box exercise rather than a genuine attempt at democratising services and moving towards power sharing, service users and survivors quickly realise this and become disillusioned:

> *'They are prepared to have users, and they are prepared to kind of say, "Yes that's really important and true and valid", but then the system doesn't change very much, if at all, so that's the real problem.'*

> *'I think one of the problems about user involvement really is we're not clear about what it means and there are not boundaries to it and what we get involved in. It's alright being involved in all the committees and all these government planning groups and government working groups, but people are not involved in their own care.'*

However, in some places, user involvement is making real changes. One respondent has been working with a colleague and the inpatients of a high-security hospital to develop a structure for patient involvement:

> *'The board has just accepted all our new proposals and it's now guidelines, it's been accepted as the structure for the hospital, and that was written basically by my colleague and I talking to the patients, then going back and writing the structure, the management never chipped in at all, we did that on our own and then the board just accepted it straight off, in fact a lot of them just totally backed it. It's taken 11 years to get it but at least it's there, they are starting to listen.'*

Observing user involvement in locality planning

Government guidelines on involving users in implementing the NSF have provided greater opportunities for local involvement. We observed seven meetings in which service users/survivors are engaged in decision making with professionals in their localities. Most of these are concerned with implementing the NSF and developing local mental health strategies. It appears that local service users/survivors at these meetings have access to a high level of decision-making power, though one observer comments that it is unclear how much power is invested in the group overall, as 'no one seemed to have the power to authorise major changes'.

Accountability and representation

At the meetings we observed, there were reasonable numbers of places allocated to service users. There were places for between two and six service user representatives in meetings with between thirteen and sixteen people present in total. One meeting allocates a quarter of the places to service user representatives.

One representative says they are expected to represent the users' perspective but this is difficult as there are a thousand people using mental health services. Most are there because their groups have been approached by the local trust. One is there as part of a paid job for a local user forum. This group, on learning of a meeting, keeps 'hammering away' until they get an invitation to attend. At one meeting, the observer notes that service user representatives are all white and therefore do not reflect the ethnic diversity of the local area. This may also be an issue at other meetings.

Accessibility and support

The venues are mainly comfortable and accessible, though two are in remote or rural areas and one meeting has a very early start. One observer found the meeting room inhibited involvement:

> *'Table too long and narrow (have to squeeze in). Hard to hear someone speak. If you want to be heard, you have to speak up, making it harder to speak, you must have confidence to be able to do this in a large room of professionals.'*
> (Observer comment)

At one meeting there was a deaf person present with a signer. This seemed to help make the meeting more accessible for everyone present:

> *'There is one person receiving sign language interpretation. The professionals at the meeting are speaking carefully, slowly, and explaining everything clearly to make it easier for the signer to interpret. This also makes it easier for everyone else to hear and understand what is happening.'*
> (Observer comment)

Training and information

Training is a major concern. User representatives from two meetings state that no training is available, though, in one area, user-led participation training courses funded by the health service are to begin soon. The rest had received varying amounts of training though felt there was room for improvement. Training included short courses on chairing, meeting skills, confidence building and use of equipment. In one case, training is run by the local user group.

We asked how well informed service user representatives are. Responses ranged from 'fully briefed' to 'no information'. Three representatives say they are sent copies of minutes, papers and agendas, although one finds them hard to follow and another says they are received the day before the meeting. Some are able to contact professionals by telephone for clarification, or have received visits to their local group to explain local developments. Only one service user representative feels unable to share information informally with professionals because of their being too 'cliquey'. One states that informal information sharing is common among service user representatives, though this is difficult because of last-minute receipt of papers.

What is expected of service user representatives?

Some service user representatives say there are high expectations on them, for instance, regular attendance, contribution at meetings and taking part in task groups. Others are asked to contribute papers to meetings. One service user representative says they have been asked to draft a user involvement strategy within a short timescale.

> *'The service user representative said that work always has to be done in a hurry – only a couple of weeks to do the user involvement strategy paper. At the beginning she didn't get asked to take home any work, now she is asked to do it and feels more included but is not paid for the work.'*
> (Observer comment)

Some say that there are high expectations that they will be familiar with the mental health system, the issues for professionals and the language used. It appears that the longer service user representatives are on committees the more their skills become recognised and the more they are asked to do. This makes them feel part of the group, valued and recognised. However, the resources to enable them to do the work well may not always be forthcoming.

Power issues in meetings

Service user representatives at three different meetings stated that they are able to put items on the agenda if they want to, though observers found that no meetings had allocated agenda slots for the representatives to put forward service user issues. Instead, agenda setting was governed first by central, rather than local, aims and second by professional agendas.

> *'All-white group. Professional perspectives being put forward. Prioritising is being discussed, but whose priorities? Medical-based discussion.'*
> (Observer comment)

Prior to one meeting, an observer asked service user representatives whether they were able to put items on the agenda or have their own slot. They explained that the agenda was set beforehand and that they did not have a slot for user issues. The point was then raised by the representatives in the meeting that followed and it was agreed that, from then on, space for users to raise issues would be made on each meeting agenda. Despite the observers having a non-participatory role, in this case a change was effected by their presence.

Four of the observers considered the meetings to be fairly relaxed and that it was easy for users to raise a point:

> *'Feels user friendly without being patronising or falling over itself to be user friendly. Naturally that way, as chair seems to be committed to user involvement.'*
> (Observer comment)

However, this was less so in the other three meetings, where there were problems such as too much jargon and too much pressure of business making it hard for users to ask questions.

> *'Quick-fire discussion between professionals, I found it hard to follow explanations of where the money from hospital closure was going – but I don't know the background. Professionals talking among themselves a lot, hard for users to get into the debate in my view. They seem too busy to stop and explain and involve users.'*
> (Observer comment)

> *'Certainly assumes a lot of prior knowledge, e.g. what each board is responsible for, etc. Depends what is being discussed therefore. Much is accessible to me and probably much more so to people from this area. Don't seem to rely too much on jargon. Feels largely user friendly.'*
> (Observer comment)

Can user involvement in locality planning make a difference?

At a few of the meetings, service user representatives seem to have a strong influence on decisions.

> *'Meeting discussed procedure for control and restraint of patients when being taken by police from a public place to the police station. A service user representative – first-time attendee of meeting gave a personal and heartfelt account of his own painful experiences when being formally detained – powerful statement. Psychiatrist was sensitive to this and asked how he would like this to be responded to. Police rep defended actions of some officers but was sympathetic.'*
> (Observer comment)

One of the representatives says it has taken considerable work to arrive at this position. Another says that he is listened to because he is not over-demanding or over-critical and is able to compromise. At other meetings, service user representatives seem to have little impact. At one meeting, the observer noted that, while user representatives can raise points, it is often not clear what decision has been made, making it hard to know whether users' points have been carried. The observer of one meeting found the meeting chair friendly yet very dominating and did not feel that users' views were actively drawn out. Another observer found that the professional view was dominant although the chair enabled all views to be expressed. Meeting chairs clearly have a crucial role in creating the opportunities for full participation. One observer was asked by the chair to feed back about what had been witnessed regarding user involvement at the meeting. This seemed to demonstrate openness to improvement.

What is working well in locality planning involvement?

Service user representatives at all of the meetings said that they did feel included, though, for three of them, this had taken some time to happen. Two representatives said this is the result of competent chairing. Some find that regular attendance over a long period helps build the trust needed for effective participation. In some cases, the numbers of service user representatives have gradually been increased to a more effective level over time. Representatives in one meeting said that, to begin with, they were not taken seriously and had little space to contribute. Now they feel more equal although their role continues to be tokenistic to a certain extent. Another said that institutional change is occurring to make genuine user involvement a possibility. However, the pace of change is slow and it is hard to see what is being achieved. Another says it is important to show willingness to compromise and remember that the trust also needs to get something out of the process.

What could be improved in locality planning involvement?

Service user representatives at the locality meetings made the following suggestions for improvement:

- As lots of paperwork needs to be digested quickly, summaries of papers would be very helpful.
- A guide to jargon and acronyms or, better still, no jargon or acronyms.
- Service users working at this level need support, training, mentoring and resources over a long period.
- New representatives could shadow current representatives to learn how to do it.
- Service users need confidence building, for example, being assured that what they have to say is important and listened to.

- Service users should be involved at all stages including planning meetings, not just attending them.
- Service users need to show that they are willing to listen to professionals and then professionals should be willing to listen in return.
- Providers need to accept the principle of partnership working, then staff will practice user involvement at every level.
- User involvement currently works through service user/survivor groups but not everybody wants to belong to a group. Therefore service users should be involved as consumers of services firstly at the individual level. Otherwise professionals can simply tick the user involvement box without real involvement.
- Professionals must recognise that service users are not represented by the voluntary sector.

Involvement in difficult decisions – policy issues in locality planning

Observers at the meetings raised a number of concerns about actual content of the meetings. They were surprised to find the low priority which service user/survivor projects were being given in the locality planning forums. It is clear there is little money available for the voluntary sector and for expanding and improving local services. In many of the meetings, the main role for service user representatives is to help prioritise what is to be cut. The priorities are set nationally and the agenda is still dominated by health. There seems to be little flexibility for local service user/survivor priorities to be considered, such as advocacy projects or minority ethnic user groups:

> *'I am shocked about the status of the user projects. The funding stream for them is due to close in four months. Who is making these decisions about funding aims and commissioning voluntary services? Next year where is the funding? They are clearly deciding funding goes to projects in being/already funded. Decisions re. funding voluntary or statutory services should be considered in relation to their benefit to the service users. How do we sustain mental health self-help service/groups without funding?'*
> (Observer comment)

> *'The meeting was a Mental Health Strategy Group. They were working out priorities for cuts. The problems were not about improving services, just keeping at a standstill. Anything lower than priority one was knocked off. They are closing a hospital but building two 24-hour staffed units – this is taking most of the money.'*
> (Observer comment)

> *'I was concerned about issues of funding for the voluntary sector – they usually get funding from slippage, but it will be more difficult to start voluntary sector projects with mental health grants coming through the health route to the Joint Commissioning Board. Social services used to fund them. Joint Commissioning seems to make funding more health dominated, there is less flexibility for the Mental Health Strategy Group to influence spending of mental health grant. Money for advocacy is not "factored into" the grant.'*
> (Observer comment).

Is user involvement a good use of time and energy?

Our findings show that user involvement is a mixed blessing for service users/survivors. While opportunities for involvement in policy making, at least at the locality level, are increasing, there are still many improvements that need to be made if they are to play an equal part as stakeholders. Their role currently, at best, seems to be to share the responsibility for difficult decisions about the allocation of scarce resources rather than being able to bring about the profound changes they want to see in the ethos of service provision. This could be argued to be simply facing service users/survivors with the realities of life. Money is scarce and professionals constantly have to make difficult decisions about how they allocate resources. Service user/survivor representatives have to learn how to take part in this and argue their case along with everyone else. But, with such a limited reward for the difficulties of getting involved, is this a good use for people's time and energy? Would we not be better to devote ourselves to providing mutual support, raising money for user-led services and campaigning for a more informed attitude to mental health issues? And what of the experience of involvement for the individuals concerned?

Does user involvement empower people or damage their mental health?

A recent service user/survivor led survey of user involvement (Harrison, 2002) found that many people who take part in it find it causes them stress and damages their mental health. The stress was caused by factors such as not being listened to, experiencing 'tokenism' and being accused by other users of being 'a professional user'. However, on the positive side, some people had found it enjoyable and said it had helped their recovery.

Similarly, we found that, where people feel they can make a difference, user involvement can help them to feel more powerful. The skills they develop and the knowledge gained can make them feel part of society again. Where it is not acted on, it can lead to frustration and disempowerment. And user involvement should never be seen as some kind of occupational therapy:

> *'I've found that being in user involvement did empower me, even in spite of all the put downs and terrible experiences that I had along the way, kind of enduring and prevailing and still being here. I think it's worth it for its own sake, but it makes me absolutely furious if mental health workers say, "Oh it's therapeutic".'*

> *'Yeah, it's empowering to a certain point, but it then becomes disempowering when it's not been acted on, and it's not getting the funding that other services are, if there is not the commitment behind it and especially to the Black community who are constantly being asked what they want, and then disbelieved and then asked again and again, and nothing comes out of it.'*

User involvement is described by some as a battle for power, which can lead to empowerment on a broad political scale. The gains may not be apparent in the short term and the struggle can be painful for the individuals concerned, who might never get the benefit:

> *'Because it is a political struggle it can be quite disempowering, at the same time if you keep at it, it can lead to broader empowerment. It's a painful business getting any change, you can sometimes achieve change through being involved, but, if you think that the involvement will necessarily be an empowering process in itself, I think you may be disillusioned. It's really about struggles for power. It can be very difficult and nasty.'*

> *'You get little victories, but I think it needs to be very focused, being realistic about what you can actually achieve. If you start with small things and you build up, your confidence gets better and that in itself empowers you, it doesn't mean that you win every battle. People get involved with big campaigns which they never see the end of, but actually their life's in a mess.'*

Some people can end up taking on too much, which is no good for them or for others. Their own overload leads them to drop out, while others are discouraged from taking on a similar role which they get the impression will be too difficult and highly skilled for them:

> *'There are some casualties, folks overstretching themselves, because they are involved in so much, they then have limited time to get other people involved and, because a small group of people are involved in everything or a lot of things, how are they then seen by people who might want to be involved but feel it's an almost exclusive club? Because people have gained certain skills which are then enabling them to be involved in committees and stuff, the more they're going on committees. In the end folks just have to drop out because of the stress of it, they're almost being killed with kindness, "Want you on this committee, on that committee", all that sort of thing. So how do I get new people involved, if the people that are involved now haven't got the time to be involved, do you see what I mean?'*

User involvement is just co-option into an oppressive system

A number of respondents believe that user involvement offers only limited benefits or is a distraction from the real issues we face:

> *'Basically user involvement is just involving service users in a system that oppresses them, and giving them posts within those services.'*
>
> *'I think there is a problem with approaches to distress and madness, and it's very easy to just acquire the approach of the services.'*
>
> *'I think there's always going to be a situation where the people who provide the money are going to dictate the shape of things. If service providers want certain types of user involvement and are prepared to pay for it, that's going to affect the user movement because a certain part of it, perhaps a large part of it, will shift to pick up that money and meet those requests.'*

User involvement is a step in the right direction, towards real cultural change

But others are more optimistic and see government directives on involving users as recognition that we have something to offer. They believe this will eventually lead to real change:

> *'The fact that the government recognises that users have a role to play shows that there is a better acceptance that people who have got problems can help in some way and are not outcasts in society.'*
>
> *'The local director of mental health, who has had in their own past an influence on user involvement, has come to this trust where there has been almost no user involvement and the government directives about involvement say that you've got to listen because how else can you respond, and because of that he has been able to actually say, "This is the direction that you've got to take", so that the people right at the top, the trust boards are able to support that. So, even right down to the most negative staff, they know that it's not just somebody's whim, that it's there from the top so cultural change is on the agenda.'*

Summary of user involvement

- For national policy making, it is particularly important to understand the movement and its various organisations, so that those invited know why they have been asked and who they are expected to represent. Reasons for involving service users/survivors, and the purpose of the consultation, should be made clear to all concerned, and particular attention paid to involving people from minority groups to ensure they are not isolated. Information and support should be available, and time for service users/survivors to meet each other.
- User involvement is becoming accepted locally and in national voluntary organisations. Opportunities to be involved exist, though this is variable and minority ethnic groups are still not well represented.
- Service users/survivors involved often do not have a local base of support and accountability, and may need skills training. There are examples of good practice where resources for capacity building of local users are in place.
- Most involvement is still in the form of traditional representation on committees, e.g. the Local Implementation Groups or Teams (LIGs and LITs). Involvement in these is working fairly well, but it can take time before user representatives feel accepted and trusted as full members. High demands are often made on representatives without the provision of the resources that professionals have. Agendas on LIGs and LITs are dominated by centralised health priorities, which are making it difficult for service users/survivors' priorities (e.g. funding of local advocacy) to be met. Often decision making is about where to make cuts rather than how to support user-led services.

- Power dynamics between professionals and users need addressing. Issues include provision of information and proper briefing, explaining jargon terms, recognising the skills and expertise that service users/survivors can offer, and making meetings accessible in terms of timing, location, transport and reimbursement of costs.
- Committee meetings dominated by professionals are not the only means of involvement; more accessible ways can be found to ensure more service users/survivors can take part.
- Professionals need training to ensure they understand user involvement and welcome it. They need to take on board partnership working and involve service users/survivors throughout, not just as members of consultative committees.
- Paying service users/survivors for involvement is good practice, and some areas have set up payment systems, but it needs sensitivity and care because of benefits issues.
- Ultimately, if service users/survivors do not see results from user involvement, they are likely to become cynical and withdraw. This sets back progress. Professionals should ensure that, if they invite involvement, they are prepared to listen to and act on it.
- Service users/survivors may have good reasons for not wanting to be involved, such as getting on with their own lives, and spending time on more fun and creative activities.
- There should be policies, plans and structures available to ensure that user involvement is properly resourced and effective.
- Where involvement is done well, it can be empowering for service users/survivors and even help their recovery, but when done badly it can damage people's mental health. People can end up taking on too much and becoming isolated from their peer group, then dropping out.
- Some service users/survivors see user involvement as co-option into an oppressive system, but others see government directives to involve users as showing signs of a cultural shift towards acceptance of service users/survivors as having a valuable input.

9

The future for the movement and user involvement

In this chapter, we look to the future for the movement and for user involvement. First, based on our findings from the research, we set out five key requirements for strengthening the movement and enabling more successful involvement. Then we set out an agenda for change over the next 50 years, covering the movement, user involvement and wider society.

Key requirements for the movement and for user involvement

Key requirement 1: unity, diversity and inclusiveness

Many respondents spoke of wanting the movement to be more united and less factional:

> *'I'm a bit concerned that there are factions here, there and everywhere. It would be nice if we all came under the one umbrella and worked together. I'm not saying disregard the issues, there are different issues for different people, but I think we'd be more powerful if we were all working as one overarching group.'*

However, we need to understand that diversity and unity are not necessarily incompatible. Differences of life experience cannot be ignored and people's confidence grows when they create a safe space for themselves as Black people, women, or people with specific experiences of the mental health system:

> *'I think it's going to be quite hard for the mainstream, predominantly white group that has not usually worked with Black people in any way, then suddenly having to. They've come together around mental health and they would not have addressed racism and other issues that will come up.'*

> *'I think we have committed individuals within the white user movement who probably want to empower the Black and ethnic minority population, but we're all human beings and we would come from different angles.'*

While we need to widen the movement and make it more able to include and represent service users/survivors generally, not everyone is going to want to get involved:

> *'When I used to attend a drop-in, people didn't talk very much about mental health issues. They talked about football and what was on the telly last night. I found that, when I tried to get conversations going about how medication works, and so on, people weren't interested. They have simply accepted that they can collect state benefits. They're not fighting against the label; they're just living their lives.'*

However, given the funding to do outreach work, research and user-focused monitoring, and to pay participants for taking part, it is often possible to find out and represent the views of people who choose not to be actively involved in the movement.

Key requirement 2: alliance with other organisations

Many respondents feel the movement will be stronger if it creates alliances with other community groups, such as Black groups and disabled people's groups:

> *'It's important that the service user movement looks for links with other minority groups, other segments of the community. Mental health issues transcend all aspects of community. Until we start making these links, I don't think it's going to be a very successful movement.'*

Key requirement 3: developing a common value base and agenda for change

There is a clearly identified need for us to develop our own ideas and be specific about how far these differ from the biomedical model of mental health:

> *'I'd like us to be clearer about how we'd like mental health to be dealt with. We need to redefine it for ourselves so that we're not just subject, all the time, to somebody else's idea of distress and mental health, because it's inevitably medical. I bang on about the medical model, because it excludes people, marginalises people and discriminates against people. It divides people who are well from people who are ill, which is a completely false division, and it's about control. I'd like to see us develop alternatives to that – alternative models that are more about us as individuals and the things we do for ourselves and which acknowledge we do actually have life skills and we have coping skills – the holistic approach.'*

In the absence of more independent sources of funding, the issue of accepting money from the pharmaceutical industry is unlikely to go away. The movement should develop ethical guidelines for groups considering accepting funding from pharmaceutical companies.

Key requirement 4: becoming more visible and proactive

Currently, the movement is not making enough impact on the general public. The best way to reduce stigma is for us to let more people see what we can achieve:

> *'Ordinary members of the public would probably sympathise with us but don't because they don't understand it. Campaigning nationally should be about showing people the good things we do.'*

Key requirement 5: coming together to reflect, discuss and move forward. Developing flexible structures and leadership

A number of respondents suggest that there is a need for an overarching national network to bring all the different movement activities together, and for ways to communicate via a journal, website and an annual event:

> *'What the service user movement should be about, at the moment, is just evaluating where we are at, what's useful to go forwards with and what isn't. It is like what we say about people working in mental health services – we need to take time out to reflect on what we are doing.'*

There is a need for structures to enable continuity, but respondents were concerned that the movement should not always be led by the same people. It is important to keep the movement flexible to deal with changing situations and new ideas, and to ensure opportunities for new people to take on leadership roles.

A suggested agenda for the movement

Respondents were asked about what they would like to see the movement achieve in the future. This agenda is based on their responses to that specific question and on the general points raised throughout other sections of the report. Clearly, many of the goals cannot be achieved by the movement alone and there will be a need for strong alliances with other community organisations, support from professionals, and from local, regional and national government bodies.

Agenda for the next two years

- Consolidate existing work and reflect on what has been done and how to develop movement.
- Create new structures to bring the movement together, e.g. a national conference, publishing a journal, a statement of shared values and objectives.
- Develop ethical guidelines on accepting funding from pharmaceutical companies.
- Provide training for service users/survivors in taking on leadership and in developing a flexible networking approach rather than highly structured and centralised organisations.
- Provide support for setting up a Black movement and start work towards eliminating racism from the general movement.
- Work towards more effective user involvement – set standards from the service user/survivor perspective.
- Better mental health services – work for end of mixed wards, better acute treatment through user involvement in staff training and use of advance directives.
- Strengthen alliances with other community organisations, including the disabled people's movement, and work together for rights and choice, e.g. advocacy and Direct Payments.
- Provide more service user/survivor led and managed services.
- Ensure no extension of compulsory treatment.
- Reach out to the general public to give positive images of service users/survivors.
- Campaign for the right to employment and end the benefits trap.

Agenda for the next ten years

- Develop strong local, regional and national bases for the movement.
- The movement to hold annual conferences, produce its own journal and support service user/survivor led research and service monitoring.
- User-led services widely available.
- Greater use of information technology to enable service users/survivors to network and share information.
- Training provided to ensure diversity in the movement.
- Black service user/survivor movement established and working alongside general movement.
- Work towards adoption of a national framework for user involvement.
- Establish user involvement in training and in appointing all mental health staff.
- Ensure advocacy is a right for all.
- Work for a reduction in compulsory treatment as more alternatives to biomedical treatment and more choices become available.
- Services oriented towards preventing mental ill health, supporting recovery and social inclusion.
- Society becoming less fearful and ignorant about mental health issues and less racist. Education provided in schools to raise awareness of children and young people.

Agenda for the next 50 years

- Strong, diverse movement having an input into all national mental health policy.
- Involvement on our own terms; equalising of power between service users, staff and policy makers.
- More humane, holistic and socially oriented model of mental health established.
- Free choice of mental health services available, including a range of non-medical services.
- Service user/survivor led services and service users/survivors employed in mental health services will be commonplace.
- Abolition of compulsory treatment.
- Strong anti-discrimination laws.
- No racism in society.
- Greater emotional literacy and more enlightened attitudes to mental health in society generally.
- Complete social integration of people with mental health problems.

> *'My hope is for people to say, "Do you know, 50 years ago, we used to say to people who'd been traumatised and abused and had terrible emotional problems, we used to say, 'You're a schizophrenic or a manic depressive and you'll always be like that'." We will look back and be horrified at the kind of things we do to one another today.'*

10

Conclusions and recommendations

Conclusions

Origins of the movement

The current service user/survivor movement originated in the 1970s and was set up by people who were angry about their treatment. Anger is still a common motivating factor but, as the movement has grown, many people may join to find support and friendship rather than for political reasons. The movement has grown and developed rapidly over the past 15 years, spurred on by social and political changes, in particular the era of community care and government requirements for user involvement. However, user involvement has also been a result of the growth of the movement, as the existence of more active groups has led to more lobbying for the right to be part of the decision-making process.

What the movement does, and what it needs

The movement consists of a large number of small local groups and a number of national networks, some of these based in large voluntary organisations but most of them independent. Most of these groups manage on insufficient and insecure funding. Despite this, they provide valued support services, advocacy and information to their members; take part in local and national decision-making committees; provide training for mental health workers and for their own members; encourage creativity, self-management and recovery; campaign for better services; and try to educate the media and the wider public about mental health. There is a clear need for more financial support on a secure and long-term basis to enable local and national networks to consolidate their work and widen their scope.

Diversity and inclusiveness of the movement

Most groups are predominantly white. There are a small number of Black groups, who are beginning to meet together and call for a Black movement to be established. Many Black service users/survivors began as members of mainly white groups and came together to set up their own groups because their issues were not being addressed and because of experiences of racism. Issues of diversity are not currently well addressed by the movement generally, though there are a number of examples of good practice and most groups are trying to widen and diversify their membership. Women are numerically well represented, though there are separate gender issues for both women and men that need to be better addressed. We did not find any examples of independent gay/lesbian/bisexual user groups and awareness of issues of sexuality was not high, again with exceptions. The movement does not currently include or represent all users of mental health services, but some user-focused research indicates that differences in views between movement members and 'ordinary' service users may not be that great.

The Black service user/survivor movement

Black groups are small, isolated and poorly funded and largely unrecognised. They urgently need more resources including money, information and practical help to enable Black service users/survivors to meet together. They may want to develop in different ways from the general movement, perhaps working with Black community organisations, but also linking with the general movement on common issues.

Common issues for the movement

There is a common agenda for the movement. Respondents generally want to be treated as individuals, not as a label. They call for staff to be trained to be more empathic and supportive, and for better acute services with more choice and less emphasis on coercion and medication. Non-medical alternatives should be available, particularly at an early stage to prevent crises arising. Compulsory treatment in the community is seen as likely to damage relationships with professionals. Independent advocacy should be a right for all. Recovery and return to employment will be helped by addressing negative stereotypes promoted in the media, and also provision of better support for families of service users/survivors.

Controversial issues for the movement

There are a number of issues that are controversial and that the movement needs the opportunity to debate. These include attitudes to forced treatment and detention, the biomedical model of mental health and its alternatives, how closely the movement should work with the disabled people's movement, funding from the pharmaceutical industry and the role of user involvement.

The role of user involvement

User involvement nationally has been problematic. The Local Implementation Groups/Teams are fairly successful in involving service users/survivors in traditional committee work and user involvement seems to be having an impact on decisions, though, currently, the agenda is centrally controlled and there are insufficient resources for service user/survivor priorities to be implemented. More people could be involved if professionals sometimes went to service user/survivor groups and used more accessible methods of involvement.

Power issues between professionals and users need addressing, and training for both groups should be available. The expertise that service users/survivors have should be valued and properly recompensed. Service users/survivors can choose not to be involved, and will do so if involvement is not genuine. More efforts need to be made to involve and support Black service users/survivors. The capacity of the movement to meet demands for involvement needs to be developed. All this points to the need for national guidelines for user involvement, and for regional and local policies and plans, with statutory funding, rather than leaving it to voluntary effort.

Recommendations

In order for the movement to reach out to greater numbers of service users/survivors and to have a substantial influence on mental health policy and service provision, there needs to be a strategy, based on a collaboration between the service user/survivor movement, the government, health and social services and voluntary organisations with the following aims:

A. To build the capacity of the movement to support and represent service users/survivors.
B. To strengthen and develop user involvement nationally and locally so that it can have a real impact on service provision.
C. To develop a new integrated prevention, self-management, recovery and inclusion focus for all mental health services and related social and employment services.

A. Building the capacity of the movement

The movement provides a valuable service to people wanting to move away from services and rebuild their lives. It has supported self-management, recovery and reintegration, and is helping to train workers, inform the media and educate the general public, usually on a shoestring budget. It deserves recognition and financial support, which should be provided with as few strings as possible. The movement needs to retain its independence in order to provide advocacy and offer critical comment on services.

Recommendation 1: enabling stronger local, regional and national service user/survivor networks
The movement should be financially resourced and practically supported to build stronger local, regional and national networks.

- Funding for this should be secure and should be given with minimum strings attached.
- Many local groups need help with finding premises and employing workers, which might best be done via the voluntary sector with statutory funding.
- Special projects should be supported to develop local service user/survivor led services, self-help and information networks via RDCs.
- There should be regional and national support for service user/survivor led research, via NIMHE's Mental Health Research Network (MHRN), MHF and SCMH.
- An IT strategy is needed to help local groups to access and use internet communication, and to develop a national movement website and online journal. NIMHE and Mental Health Media may be helpful in this.
- There should be a funded national support organisation for service user/survivor workers. This could be linked to a general trade union such as General Municipal Boilermakers (GMB) or Transport and General (T&G).

Lead for local and regional development: NIMHE regional development centres (RDCs), primary care trusts (PCTs), strategic health authorities (StHAs), local councils for voluntary service (CVS).

Lead for national development: NIMHE, SCMH, MIND, Rethink, Mental Health Foundation (MHF).

Recommendation 2: development of a national voice for the Black service user/survivor movement
This was also recommended by the recently published SCMH report *Breaking the Circles of Fear* (The Sainsbury Centre for Mental Health, 2002).

- Development funding is required to enable leading Black service users/survivors to come together regularly and start a process of outreach and discussion with Black service users/survivors around the country.
- Based on this work, secure funding is likely to be required to develop the capacity for local groups to be set up to provide mutual support and a base for greater involvement in decision making.

Lead: NIMHE, SCMH.

Recommendation 3: increasing the movement's capacity to represent diverse experiences

- A national programme should be developed to make available to service user/survivor groups quality training to eliminate any possible racism and homophobic attitudes and to raise awareness of disability issues.
- This training could be co-ordinated by UKAN and/or Mindlink with practical support (e.g. venues and equipment) from RDCs. Appropriate trainers and courses could be recommended by the Commission for Racial Equality (CRE), PACE (organisation for gay and lesbian mental health) and the British Council of Disabled People (BCODP), and adapted to a mental health context.

Lead: NIMHE RDCs and Experts by Experience Group, UK Advocacy Network (UKAN), Mindlink.

B. User involvement in improving services

National guidelines for user involvement should be developed and implemented. Service user/survivor priorities should be integrated into the NSF for Mental Health when it is next revised.

Recommendation 4: development of national good practice guidelines for user involvement
A task force should be set up to develop a set of national guidelines for user involvement, based on the Draft Principles on User Involvement in this report (p. 63). The DoH should then issue guidelines to StHAs, PCTs and NHS trusts.

Lead: NIMHE Experts by Experience Group, leading service user/survivor networks.

Recommendation 5: revision of the NSF for Mental Health to include user perspectives on services
At the point when the NSF is next revised and updated, NIMHE (through its Experts by Experience Group) should co-ordinate a consultation exercise on how to integrate service user/survivor perspectives into the revised Framework.

Lead: DoH Modernisation Agency and NIMHE.

C. A new integrated prevention, self-management, recovery and inclusion focus for all mental health services and related social and employment services

Recommendation 6: a national forum to refocus mental health services towards prevention, early intervention, recovery and social inclusion
NIMHE should host a forum to discuss refocusing mental health services towards prevention, self-management, recovery and social inclusion. This could draw on the work of the existing NIMHE expert groups and link with other bodies such as the Social Exclusion Unit and other relevant government departments. This would then provide a basis for research and development to revitalise mental health services around a new value base closer to that proposed by the service user/survivor movement.

Lead: NIMHE Experts by Experience Group and the NIMHE Values Project.

Bibliography

Barnes, M. and Bowl, R. (2001) *Taking over the Asylum: Empowerment and Mental Health.* Basingstoke: Palgrave.

Chamberlin, J. (1988) *On Our Own*. London: Mind

Harrison, M. (2002) *Hurt involved?* (Unpublished report.)

O'Hagan, M. (1993) *Stopovers on My Way Home from Mars.* London: Survivors Speak Out.

Rogers, A. and Pilgrim, D. (1991) Pulling down churches: accounting for the British mental health users' movement. *Sociology of Health and Illness,* **13** (2) 129–148.

The Sainsbury Centre for Mental Health (2002) *Breaking the Circles of Fear: A Review of the Relationship between Mental Health Services and African and Caribbean Communities.* London: The Sainsbury Centre for Mental Health.

Snow, R. (2002) *Stronger than Ever, the Report of the Survivor Workers' Conference.* Manchester: Asylum Publishing.

Appendix 1: Glossary and discussion of terms used in the report

There are always many discussions on the terms used in mental health. It is important to be clear on what we mean by the terms we use and what they mean to the people interviewed.

We have used the term 'service user/survivor movement' to refer to the movement that we believe exists and that we, as authors, feel we belong to. We have referred to this throughout as 'the movement' and the definition of the movement was consulted with the respondents and generally agreed.

We are aware that not everyone who has used or received mental health services or has experienced mental or emotional distress or illness will refer to themselves as service users or survivors, but these are the main terms that are currently in use.

However, during the research, we were keen to find out what people think of these terms. While most people do not have any major objection to either term, some do have strong reactions either for or against one or other term.

'Service user'

The term 'service user' or 'user' is often seen as referring to those who use mental health services and are more concerned with service reform and improvement than with radical challenge. However, some people strongly dislike being called 'users' as it sounds like 'drug user' or someone who uses other people. Others feel they did not choose to use services.

'Survivor'

The use of the term 'survivor' is seen as implying that the person has come through traumatic experiences (related to their mental health and/or mental health services) and is committed to campaigning for change. In some cases, it is used by people who no longer depend on services. Some respondents find this term more positive than 'service user', while a few think it is too dramatic and divisive.

Some people suggested alternative terms that could be used instead of 'user' or 'survivor'. One group refers to people with 'primary' experience of mental health services (service users or survivors) and people with 'secondary' experience (family, friends and carers).

What is user involvement?

The term 'user involvement' is used in this report to mean the various ways in which mental health service users/survivors are helping to change mental health and social services. This often works through service users/survivors becoming members of committees along with professionals and people from voluntary organisations, though it can include a number of other ways, such as conferences, discussion forums, open days, service users/survivors acting as paid consultants, or professionals visiting user/survivor groups.

What is a social movement?

Sociologists argue that, as heavy industry declined in the second half of the twentieth century, social movements became less related to social class and economic issues (e.g. the trade union and labour movement) and more about single issues and personal politics, such as the women's movement, Black power, environmental and peace movements. Rogers and Pilgrim (1991) describe the British Mental Health Users' Movement as an example of a post-industrial new social movement.

Throughout this report, we have assumed the existence of an identifiable service user/survivor movement, while at the same time allowing for people we interviewed to contradict this assumption. People in the movement do not have to be conscious of being part of a movement, but only of sharing some common goals and of moving in a similar direction. We believe this report confirms the existence of a movement according to this definition.

Categories of ethnicity used in the survey

For details of ethnicity categories used see Appendix 3.

There is little data relating to ethnic groups other than for those of African-Caribbean, Asian or Black British groups. We have defined all these groups as Black, and this is how they are referred to throughout the report except where there is a reference to the particular sub-group they identify with. In direct quotes, we have not changed the language about ethnicity that interviewees use.

Empowerment

We asked people in the survey their views on what 'empowerment' means. Individual empowerment is seen as including:

- personal development;
- growth and recovery;
- regaining personal power;
- gaining or regaining skills and self-belief;
- making one's own choices about one's own independent future.

Collective empowerment is seen as including:

- raising awareness of shared oppression, culture and history;
- peer advocacy and mutual support;
- gaining access to information, credibility and power to be equal with doctors and managers.

The biomedical model of mental illness

When survivors/service users talk about 'the medical model', they are usually referring to the assumptions underlying most psychiatric research, diagnosis and treatment, or saying that there is an underlying physical cause of mental or emotional distress, or that distress can be treated as if it were physical. This model is more accurately called the 'biomedical model of mental illness', to indicate that its emphasis is on biological rather than social reasons for mental illness. There are in fact a growing number of psychiatrists who are more inclined towards a social model.

The social model of disability/mental distress

People talking about the social model in mental health may be referring to the causes of mental or emotional problems. The social model view is that mental health problems generally come from early life experiences or later shocks and traumas rather than having a physical origin. This means that the solutions should also be primarily social, e.g. talking treatments and practical support. The social model in mental health may also be based on the disability movement approach, i.e. that the main problems that most service users face do not result from their impairment, but from other people's attitudes and social discrimination generally. This leads to campaigns for greater rights and access, to remove blocks to equal standards of living.

Mental health service user/survivor perspectives on mental/emotional distress

Mental health service users/survivors have developed their own perspectives on mental/emotional distress, disability and illness, which may include aspects of the above two models but will generally include a stronger emphasis on empowerment, self-identification of problems, being listened to, choice of intervention, self-management of problems, practical issues such as money and housing, and the importance of a focus on recovery and wellness rather than illness.

Appendix 2: Methods used in the postal survey

Sample reliability

The method employed may mean that groups affiliated to national organisations are over-represented. However, the mapping form did attempt to use the contacts gained from national organisations' mailing lists as the initial stages of a 'snowball' method. When groups were asked whether they had national links, 62% stated that they did, while 77% said that they had local links. This suggests that the snowball method was successful in reaching groups that were not on the mailing list of a national organisation.

Representation of diverse groups

When the databases were developed, it became apparent that there were very few Black and minority ethnic groups. This led to the commissioning of another database specifically for diverse groups. This diverse database was created by telephoning existing contacts and posting a survey form to Black and minority ethnic organisations. This survey form was far more detailed than the original as groups being contacted were not necessarily mental health or user led or run. Additional information required included a brief description of the organisation, whether there was a user group attached and whether they knew of any diverse user groups operating in the area. This increased the number of groups on the database by around 20. As the response to the postal survey form was fairly low, groups were then telephoned to complete the survey form over the phone.

An attempt to reach Black and minority ethnic groups was also made by posting a notice on various prominent mental health internet sites explaining the research and asking groups to make contact. While this did result in a number of enquiries, it did not increase the number of groups in the sample.

Overall, the work increased the number of Black and minority ethnic groups and organisations on the database to 199. We also attempted to increase the numbers of lesbian, gay and bisexual groups represented in the sample (initially none were included). A mailing was sent to a national mental health organisation for lesbian, gay and bisexual people, which resulted in three lesbian and gay groups being added.

Sample cleaning

Creating databases of all user groups in England has, to our knowledge, not been attempted before and the immensity of such a task cannot be under-estimated. Much time was dedicated to cleaning the databases, which was in part due to the fluid nature of user groups. Common problems included groups no longer existing, not being a mental health group or not being run or led by users. Database cleaning was also carried out to ensure that groups were on the correct database. This highlighted the problem of how to define a user group.

Definition of a user group

The focus of the postal survey was entirely on user led or run groups. As will be seen, many groups were telephoned and asked whether they were user led or run and where the majority of decision-making power lay. It became apparent that many groups found it hard to define themselves, particularly as the boundaries between user led and not are often very blurred. Furthermore, their decisions may not have related to decision-making power.

Information given by groups over the telephone seemed to be affected by many factors such as who was spoken to, whether they knew who had the power to make decisions or control the direction of the group, what they understood user run or led to mean and so on. Identifying where decision-making power was held became the most valid means of deciding whether a group was user led or run. For example, one group representative confirmed that the group was user run. When asked if the users had the power to make decisions, he vehemently replied, 'Don't be ridiculous, they're all mad'!

The final definition employed for these groups therefore relates to decision-making power. 'User only' refers to a group where it is only users taking decisions and 'user led' to a group where the majority of decision-making power lies with users, for example, through being a majority on a management committee.

Because of the problems of self-definition of user status, we would suggest that anybody wanting to undertake similar research in the future includes 'user involved' as an option alongside 'user led' and 'user run'. This may allow groups to present a positive image of user involvement without having to state that they are user led or run. A clear definition of each option should also be given as the boundaries between user led and not are extremely blurred.

Sample validation

In defining user groups, two different streams of work emerged. As the initial general database consisted of over 1,000 groups, it was clearly not possible to telephone all groups to find out whether or not they were user led or run. Instead, groups were telephoned after they had returned a questionnaire. At this stage, 64 groups were excluded for not being user led or run, leaving a total of 307 in the final sample (Table 7).

Conversely, the diverse database was small enough to telephone groups before they were sent a questionnaire. A questionnaire was then sent to all groups who appeared to fit our criteria of user led or run. This approach was hampered by problems associated with self-definition as has been discussed. Therefore, we also employed an expert in the field, who was also a member of the Steering Group, to report the status of each group based on prior knowledge of the field. This resulted in the final number of valid responses from diverse groups being reduced from 24 to 11, including one lesbian, gay and bisexual group (Table 7).

Through the processes of sample cleaning and validation, the general databases sample was reduced from 1,022 groups to a total of 798, while the diverse groups sample was reduced from 199 to 97 in total, with the three lesbian, gay and bisexual groups within this being reduced to one (Table 7). Within these cleaned samples, there was a total response rate of 35.5%. However, the response rate for Black and minority ethnic groups was just 10%, while it was 38.5% for general groups.

The final sample (after all checks for validity)

Despite the problems previously described, our final sample would appear to be one of the most comprehensive databases of mental health service user groups in England.

Table 7 – The postal survey sample

Database	Original number on database	Valid sample (number on cleaned database)	Number of deleted questionnaire returns	Number of questionnaires in final sample
Eastern	89	69	8	17
London	180	124	7	45
Northern & Yorkshire	114	90	3	39
North West	146	126	9	46
South East	199	162	14	62
South West	89	67	6	30
Trent	82	67	6	30
West Midlands	123	93	10	38
Regional totals	1,022	798	63	307
Black and minority ethnic	199	97	14	10
Lesbian, gay and bisexual	3	1	2	1
Totals	1,224	896	79	318

Representation of Black and minority ethnic groups

Clearly, despite great efforts, diverse groups form only a very small part of the sample to the extent that it has not been possible to analyse separately the data gained from the postal survey.

The reasons for the small number of Black and minority ethnic groups in the sample was discussed with the Steering Group and numerous possible explanations were suggested. These can be summarised as lack of identification and a low response rate.

There may simply be far fewer numbers of diverse groups than general groups and those groups that do exist may tend to be run by professionals or people from a similar ethnic background rather than users. It is equally possible that Black groups meet more informally, are unfunded and may not be listed on any mailing list. Large user groups and organisations may not want to include smaller groups, which might ultimately compete with them for funding. Constructing the database via national organisations did not help us to identify such groups. It was suggested that researchers wanting to access Black groups in the future should do so through active outreach and particularly through more networking in specific geographical areas. Contact should be made face-to-face for a longer time period rather than through national mailing lists. The low response rate of diverse groups may have been due to groups not wanting to take part in a project that is white dominated. They may be over-researched without seeing any results, changes or benefits. It was also suggested that white organisations consistently fail to involve Black people and that the lack of representation of Black people in research will continue as long as Black service users/survivors are disempowered, including by Black professionals.

Factors that may have affected the response rate of mental health user groups in general were also suggested. The name the 'Sainsbury Centre for Mental Health' may have led to some confusion, despite the role and function of the organisation being clearly explained in the first letter. Groups are generally overworked, and the research coincided with lots of changes that users and user groups may have been involved with. As some user groups were too busy to participate, it was suggested that future researchers should offer the group a fee for taking part.

A database of this type has never been constructed before and, despite problems, this would appear to be the most reliable and comprehensive in existence. The inclusion criteria are clear, with groups being user led or run as defined by majority decision-making power. While there were problems in the identification and low response rate of Black and minority ethnic user groups, the overall response rate was 35.5%.

Appendix 3: Categories of ethnicity used in the study

White
White British
White Irish
Other White

Shared heritage
White-Black Caribbean
White-Black African
White-Asian
Other shared heritage (please specify)

Asian or Asian British
Indian
Pakistani
Bangladeshi
Any other Asian background (please specify)

Black or Black British
Caribbean
African
Any other Black background (please specify)

Chinese or other ethnic group
Chinese
Any other (please specify)

Results

Asian + Asian British: 6
Indian: 5
Black + Black British: 4
Caribbean: 5
Chinese: 1
Shared heritage: 2
Irish-Indian: 1
White British: 58
Scottish: 1
White Irish: 1
White – other: 4
Jewish: 1
Romany: 1

Appendix 4: In-depth research methods

Qualitative methodology

Aims

- To follow up the results of the postal survey with a more in-depth exploration of the key themes of the research.
- To shed more understanding on the nature of the work that service user/survivor groups are doing, the experiences of local and national active and less active members of the movement, their views on the movement and their wishes for the future of the movement.
- To explore service users'/survivors' experiences and views on user involvement, and find out how they think its effectiveness can be increased.
- To keep the research user led by recruiting a team of service users/survivors with research experience to help collect the data.

Methods

- One-to-one (mainly telephone) interviews with national figures in the movement.
- One-to-one interviews with people who were involved in the consultation on the development of the NSF for Mental Health.
- Selection of a sample of service user/survivor groups from those that replied to the postal survey, for follow-up visits, interviews and focus groups with group officers and members.
- Observations of meetings where service users/survivors are involved in local planning along with professionals.

Our aim in selecting people to interview and groups to visit has been to ensure maximum diversity of our sample. This is what is generally called a 'purposive sample' rather than a 'random sample'. In terms of the national figures, we sought to ensure maximum diversity of ethnicity, gender and geographical location. In terms of the groups we visited, we sought to ensure diversity of geographical location, including both rural and urban areas, and tried to include a substantial proportion of groups catering specifically for people from minority ethnic groups, gays and lesbians.

The selection of national figures was made after extensive discussions with the Steering Group. A list was drawn up of people who are seen as pioneers of the movement and people who are currently running nationally important service user/survivor led organisations, including a number from a minority ethnic background. We were able to interview 29 people from our list of 35 suggested names.

The groups were selected from the eight NHS regions in England. From each region we selected one health authority area (two in London because of the high population, plus two in the South West to increase the representation of groups from rural and less populated areas) from which we had received responses from a sizeable number of groups. This amounted to ten health authority areas. We ensured that the relatively few areas containing groups specifically for ethnic minorities were included in the sample. Once we had selected the areas and made a list of all the groups in that area who had responded to our questionnaire, we selected all the minority ethnic groups and made a random selection from the other groups. In this way, we selected three groups from each health authority area on our list (30 groups in all). We then wrote to all these groups inviting their participation. They were asked to:

- select a group leader or worker to be interviewed;
- help us locate a planning group (e.g. a Local Implementation Group for the National Service Framework) with user representatives involved and seek permission for us to send an observer to one meeting;
- send out letters from us to invite a member who does not attend many group meetings to be interviewed;
- help set up a focus group in the locality to which a small number of members of the three selected groups in that health authority area would be invited;
- host a visit to their premises from one of our interviewers.

This was a lot to ask and, understandably, some groups were unable to spare the time to help us. In some cases, we were able to select another group in the same health authority area to take part instead. Ultimately, 25 groups did participate in this programme of research (see Table 8). We were able to cover any expenses incurred in setting up focus groups and paid £15 to each person interviewed or taking part in a focus group.

The interviewers took part in a training day at SCMH, and used a topic guide for the questions they asked individuals and focus groups, and for the visits and observations. Interviewees were told that the person interviewing them was a service user/survivor and, as far as possible, ethnic backgrounds of interviewer and interviewee were matched.

All interviews and focus groups were tape-recorded, transcribed, and analysed using *WinMax 2000* software. Project visits and observations were recorded as written notes on a form, and were typed up and analysed using *WinMax*.

Table 8 – The in-depth research (interviews and focus groups)

	Local groups	Individual interviews	Focus groups (average attendance six people)
Groups taking part	25		
Visits to groups	17		
Group members		18	
Group officers		24	
National figures		30	
Focus groups – local			5
Focus groups – national			1
Totals		72	6

Appendix 5: Copy of information sheet and consent form given to participants in the research

INFORMATION FOR PARTICIPANTS

What is the Sainsbury Centre for Mental Health?

It is an independent charity, based in London, which works to improve mental health services nationally.

What is the purpose of the study?

To find out about the user/survivor movement in England – its history, diversity, philosophies, activities, aims and scope. We also want to know about user involvement and what needs to happen to make this more effective. We hope this information can be used to support good practice in consultation and involvement. All the interviewers are themselves users/survivors of mental health services/mental distress.

What are you being asked to do?

You are asked to take part in an interview or focus group (interviews are expected to take about one hour, focus groups about two hours).

Can I withdraw from the study at any time?

Yes. You can stop at any time during the interview and you won't have to answer all the questions if you don't want to.

Will the information obtained in the study be confidential?

Yes. Anything you tell the interviewer will be tape-recorded and transcribed, and will be used only for this study. Your name will not appear in any report and care will be taken to ensure that individuals cannot be identified from details in any report of the study results.

What if I wish to complain about the way in which this study has been conducted?

If you have *any* cause to complain about any aspect of the way you have been approached or treated during the course of this study, please contact the project co-ordinator:

Jan Wallcraft
Senior Researcher
The Sainsbury Centre for Mental Health
134–138 Borough High Street
London SE1 1LB

Figure 7 – Consent form

RESEARCH CONSENT FORM

TITLE OF PROJECT:
SURVEY OF THE USER/SURVIVOR MOVEMENT IN ENGLAND

Have you read the Information Sheet?	YES/NO
Have you had an opportunity to ask questions and discuss the study?	YES/NO
Have you received satisfactory answers to all your questions?	YES/NO
Do you agree that your interview can be used in this research study?	YES/NO

Signed .... Date..............................

(NAME IN BLOCK LETTERS) ....

Appendix 6: Sample topic guide

Part One A – Being a group officer

I am going to start the interview by asking a few questions about your experiences of being a group officer.

Q1. Can you tell me a little bit about how you first got involved in user groups?

Q2. Why did you first decide to get involved with a user group?

Q3. Can you tell me a bit about what it's like to be a Group Officer?

Part One B – About the group

Q4. What are the main purposes of your group?

Q5. What do you feel the main achievements of your group are?

Q6. How does your group relate to your local community?

Q7. To what extent do you feel your group has an impact locally?

Q8. Would you describe your group membership as coming from diverse backgrounds?

***If yes to Q8,* Q9.** How have you achieved a diverse membership?

***If no to Q8,* Q10.** Have you chosen to cater for one particular type of member?

***All,* Q11.** Have you tried to make your membership more diverse?

Q12. Does your user group exist within a non-user led organisation?

***If yes to Q12,* Q13.** How well does this work?

Part Two – Mental health services

Q14. I want to find out your views of mental health services in general. In your general opinion, do you think mental health services are basically good as they are or do they need to be improved?

***If they think services need to be improved,* Q15.** Do you think services should be improved, transformed or replaced by something completely different?

Part Three – The user movement

Q16. What do you understand by the term, 'the user movement'?

Q17. To what extent do you feel a part of this movement?

Q18. What do you think the main aims of the movement as a whole should be?

***If they know about the user movement,* Q19.** Many people have said that the user movement has grown rapidly in the past 15 years. Do you agree with this?

***If yes to Q19,* Q20.** Why do you think this is?

Part Four – Issues of equality

Q21. To what extent do you think the user movement meets the needs of people from minority ethnic groups?

***If yes to Q21,* Q22.** How do you think the movement could address the needs of other groups more effectively?

Q23. To what extent do you think the user movement takes account of issues for women?

***If no to Q23,* Q24.** How do you think the movement could address women's needs more effectively?

Q25. To what extent do you think the user movement takes account of issues for lesbians, gays and bisexuals?

***If no to Q25,* Q26.** How do you think the movement could address lesbian, gay and bisexual issues more effectively?

Part Five – User involvement

Q27. Have you ever been a user representative at a meeting with mental health professionals?

***If yes to Q27,* Q28.** From your experiences, how much influence do you think that user involvement has?

***If yes to Q27,* Q29.** What kind of support do you feel is needed for user involvement to work well?

***If no to Q27,* Q30.** Is there any reason that you haven't been involved as a user representative?

Part Six – Issues for the user movement

Q31. To what extent do you think users share common goals or are there major differences among them?

Q32. The government is planning to make changes to the 1983 Mental Health Act. What do you think should and should not be in a new Mental Health Act?

Q33. What do you think about pharmaceutical companies funding user group activities?

Q34. To what extent do you think the user movement should become part of, or work more closely with, the disability movement?

Q35. How representative do you think the user movement is of the views of users who are not actively involved in any user group?

Q36. What do you understand by the term 'empowerment'?

Q37. What do you think the user movement should be aiming to achieve in the future:
a. first of all, the near future (the next two years);
b. the longer-term future (the next ten years);
c. the very long term (the next 50 years)?