

# Cases for Change: User Involvement in Mental Health Services and Research

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## Abstract

*This article describes our experience of involving mental health service users in research on adult mental health services. In addition to describing the advantages of and barriers to user involvement in mental health services, the article also outlines some of the key benefits and challenges of user involvement in the research process itself.*

**Keywords:** user involvement, mental health research, systematic reviews, user research

## Background

In 2002, the newly formed National Institute for Mental Health in England (NIMHe) commissioned a research team at the University of Birmingham to undertake a narrative review of the literature on adult mental health services (1997-2002) (Glasby *et al.*, 2003a). Entitled *Cases for Change in Mental Health*, the review was designed to:

- Collate evidence from published and grey literature in both synthesised and non-synthesised formats on the evidence for reform in mental health services.
- Review and synthesise all the information collected into key themes or issues.
- Present the evidence in a manner that is accessible and useful to a wide audience including policy makers, service purchasers and providers, and users and carers.
- Suggest cases for change drawn from this evidence base.
- Disseminate the evidence in an effective manner.
- Support and accelerate service improvements through spreading good practice, informing clinical governance and supporting the development of modern responsive health and social care services.

The study was commissioned and written at a time when mental health services were undergoing substantial changes as a result of the government's *Shifting the Balance of Power* reforms. Under this initiative, Health Authorities were being abolished and Primary Care Groups were becoming Primary Care Trusts, with much greater responsibilities for commissioning and delivering local health care. Against this background, mental health services were tending to move either to primary care (which may not always have a detailed understanding of mental health issues or track record in delivering

mental health services) or to much larger, specialist mental health trusts based on the amalgamation of a series of local provider organisations. As a result, NIMHe was keen for a flagship document that would guide these new agencies through a complex process of organisational upheaval and provide an accessible guide to new managers in new agencies, quite possibly taking on responsibility for mental health for the first time. In the process, the report was intended to summarise how mental health had got to where it is today and highlight what works and what does not work so well in adult mental health.

In the event, the commission we received was a demanding one, and the research team identified several thousand documents from their initial search of the literature. With detailed inclusion and exclusion criteria, these were narrowed down to some 658 papers and books which needed to be obtained, classified, analysed and synthesized within a short space of time (a total of seven months for the whole project). Findings were then written up in a boxed set of ten reports which sought to explore the key issues for adult mental health in a range of different areas:

- Mental health policy
- Primary care
- Community services
- Hospital services
- Forensic mental health
- User involvement
- Partnership working in health and social care
- Anti-discriminatory practice
- Emerging areas of service provision (which included services for carers, direct payments, new technology and deliberate self-harm)

The final report was then launched at a national NIMHe event in Liverpool in 2003 and several thousand copies distributed via NIMHe's eight regional development centres. At the same time, the report was made available via the homepage of the NIMHe website and has since been

disseminated through a number of peer-review academic articles and conference papers (see for example, Glasby and Lester, 2004o Lester *et al.*, forthcoming). In addition to a series of recommendations about each of the individual reports, the study also identified four key underlying issues which seemed to cross all of the above categories:

- The need for greater partnership working and a whole systems approach.
- The importance of values rather than structures in terms of improving mental health services.
- Longstanding barriers to change (which mean that we have known about many of the current problems in mental health services for a long time, but not resolved them).
- The importance of including a range of different types of evidence (including material by practitioners and service users) in order to understand the range of different views and perspectives).

### ***User Involvement***

User involvement was a central focus of our bid in a number of different ways and at every stage of the project:

1. A collaboration between two University departments (the Health Services Management Centre and the Department of Primary Care and General Practice) with SUREsearch (a body of mental health service users who conduct user-controlled research).
2. The involvement of a service user in the interview after our bid was shortlisted.
3. A mental health service user as a member of the expert panel advising the research.
4. The involvement of local service users and carers in defining initial search terms.
5. The recruitment of a former mental health service user to work as a core part of the research team, helping to draw out and understand key themes across all topic areas, but taking specific responsibility for reading the literature and producing the report on user involvement.
6. The inclusion of a range of literature that often gets screened out of official reviews as grade five or ‘anecdotal’ evidence. This included material in practitioner journals and written by service users.

7. The inclusion of critical commentaries at the end of each report, written by individual practitioners and service users in different parts of the country. These were designed to provide an individual response to our findings from someone with experience of the mental health system, and had a key part to play in the project (see below for further discussion).
8. The active involvement of the service user researcher at the launch conference and in further dissemination (for example, as an author of this article).

### ***The benefits of user involvement: in mental health services***

Within mental health services, the study identified a range of benefits from involving service users in the design and delivery of mental health services (see figure 1).

Additional benefits of user involvement are also identified by the National Schizophrenia Fellowship (now Rethink) (1997: 3):

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

### ***The benefits of user involvement: in research***

Within a research context, we believe that user involvement at the different stages of the project outlined above was a defining feature and critical component of *Cases for Change*. In particular, having a service user as a core member of the research team helped to ensure that emerging themes and trends were interpreted not merely from an ‘academic’ or ‘professional’ perspective,

### Figure 1 - Benefits of user involvement

1. There is a widespread recognition that service users are experts, with an in-depth knowledge of mental health services and of living with a mental health problem. By definition, no one else - no matter how well trained or qualified - can possibly have had the same experience of the onset of mental illness, the same initial contact with services or the same journey through the mental health system. These experiences are an important resource that can help to improve individual packages of care as well as services more generally.
2. As a result of their experience of mental illness, service users have developed a range of coping mechanisms and survival strategies that help them to manage their mental health problems and go about their daily lives as best they can. If mental health practitioners do not tap into this expertise, they make their own jobs much harder by focusing on users' weaknesses rather than building on their considerable strengths.
3. Service users and mental health workers often have very different perspectives. As a result, involving users can provide extremely rich data which prompts practitioners to re-evaluate their work, challenges traditional assumptions and highlights key priorities which users would like to see addressed.
4. Users have been able to develop alternative approaches to mental health that might help to complement existing services or suggest new ways of thinking about mental health. Examples include the importance of alternative and complementary therapies or initiatives such as crisis cards and advance directive schemes so that people can specify in advance what they want to happen if they become unwell.
5. User involvement can be therapeutic, enabling people to feel that they are being listened to and that their contribution is being valued. Helping to shape services - particular when users work together collectively - can also help people to increase their confidence, raise self-esteem and develop new skills.

(Glasby *et al.*, 2003b)

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but could also be viewed from a 'user' perspective. It is often assumed that literature reviewing is a completely objective task based on defined search terms, analysing and synthesising results and producing conclusions. While there is an element of truth in this with regard to reviews of more quantitative studies, narrative reviews of broad-ranging literature, like *Cases for Change*, are more subjective. While we feel that the grounded analysis approach which we used to identify key messages from the research was a robust and appropriate one, a different research team from different professional backgrounds may have chosen to prioritise different issues or to present them in slightly different ways. As a result, having a research team which consisted primarily of a GP, a social worker and a service user meant that the team as a whole could discuss these issues, challenge each other's interpretations and collectively make sense of the literature, producing a series of reports which drew on a range of different perspectives. To us, this is crucial, as there are a number of voices (particularly those of

service users) which tend to be downplayed whenever delivery or reform of mental health is discussed and we endeavoured to make sure that such voices were incorporated at the heart of our study (see below).

In addition, one of the most significant things we did as a research team was to change the title of the study from *The Case for Change* to *Cases for Change*. This was an early reflection of the many different ideas and views which quickly began to emerge from the literature. Soon it became very clear that there was no single 'case for change', but instead a series of 'cases', with different stakeholders holding different views about the nature and causes of mental illness, the best way of responding to mental distress and the way in which services should be organised. As a result, much of our study was devoted to emphasising the diversity of views and enabling these different voices to be heard. This was done in a number of ways, including the different backgrounds of the research team, the inclusion of critical commentaries to

**Figure 2 - Benefits from a user perspective**

- The opportunity to interact with other people in the context of work.
- The opportunity to resurrect skills which appeared to be lost from so many years of concentrating on recovery from mental breakdown.
- The ability to acquire new skills and further knowledge.
- The possibility of enhancing self esteem and self confidence, both of which are severely damaged by the experience of having one's entire life called into question which can happen when you fall victim to a mental illness.
- The opportunity to earn some money.
- The chance to apply the knowledge and experience gained from having been through and overcoming many of the difficulties caused by mental health problems.
- The realisation that other people are aware that lived experience is valuable and that your views are important. For anyone to recover from a severe mental illness is a triumph in itself, both for the person involved and for what he or she brings to the question, "How did you do it?"

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capture personal responses to our findings and the inclusion of literature from a range of different sources. Typically with systematic reviews, the methodology leads to the identification of a large number of documents, but tight inclusion criteria and rigorous statistical manipulations mean that very few studies can be included as part of the final analysis. However, our approach was to conduct a broad search and to include material which represented a range of different research methods (both quantitative and qualitative) and which was written by a range of stakeholders (from traditional academics and policy analysts to practitioner literature and user-led research).

Finally, having a service user as part of the team made other team members try to consider how users would think and feel in mental health services and when reading our report. It made us challenge

our own assumptions, consider our language and to be very honest and open with ourselves about our attitudes and values. As health and social care professionals, this process also helped us to reflect on the way in which the services for whom we work/have worked treat some of their service users and how this may feel.

From a user perspective, the study also had a number of strengths in supporting a mental health service user to return to paid employment, increasing skills and confidence and boosting self-esteem (see figure 2).

***Barriers to greater involvement in mental health services***

Despite the benefits of user involvement and despite significant progress in recent years, levels of user involvement remain patchy and there is

**Figure 3 - Users' Views about the Level of Involvement**

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

Adapted from Carpenter and Sbaraini

scope for considerable progress. In South East England, for example, questionnaires and interviews with 109 service users revealed a considerable lack of involvement (see figure 3), while Rose's (2001) work with over 500 users across seven sites found very low levels of involvement in individual care planning and in the planning and delivery of services more generally. In addition, Webb *et al*'s (2000: 281) survey of 503 patients across five NHS Trusts found a lack of involvement in the care planning process and a failure to respond to several prominent and longstanding criticisms from the user movement:

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

In seeking to explain the current limitations of user involvement, the *Cases for Change* literature identifies a number of barriers to further progress (see figure 4).

#### **Barriers to greater involvement in research**

Despite our good intentions, our experience of user involvement in research in the context of *Cases for Change* had a number of positive features, but also a series of limitations. Chief among these was the consequence of our decision to recruit only one service user to be part of the team, without making better arrangements for peer support. This resulted in a situation where one person returning to work was responsible for carrying out a large amount of reviewing and had little back-up. Whereas the University-based members of the team were used to delivering large reports within very tight timescales, these may well be new skills for someone from a different background and can be very stressful. In addition, the guidance offered by the expert panel, set up to comment and critically appraise the review, may also have resulted in unintended outcomes. While the panel was crucial in making sure that our work was rigorous and robust, the necessary but sometimes very challenging questions that were asked could be interpreted as being critical by someone not used to

the practices and culture of expert panels. After four months in post, the pressure of work contributed to the service user researcher becoming unwell and taking time out from the study to recover. As a result of this, she continued to comment on literature, to assist with analysis and to read draft reports, but did not write the user involvement report as had originally been planned.

For us as a research team, this was a very difficult situation. On a practical level it meant that we had to take on additional responsibilities which had not been anticipated. However (and much more importantly) on a personal level, we had to come to terms with the fact that our efforts to involve users in research had made someone unwell and that we had not provided sufficient support. For people writing about responsiveness to the needs of users, it was a major irony and an important lesson that we had become so focused on delivering the research on time that we failed to notice that a valued colleague was feeling under excessive pressure.

In addition, employing a service user as part of the research team raised a number of practical issues which we as researchers (and academic institutions as a whole) need to address. These included organising payments to the service user researcher in a way that recognised her expertise and contribution, but which did not interfere with incapacity benefits. When negotiating this with finance and personnel, there was a failure by wider support services to recognise the importance of involving service users in research and many of these services seemed unable to understand that someone could be a researcher on a high profile national study while at the same time being a person recovering from mental illness.

#### **Conclusion**

Overall, we feel that *Cases for Change* was a detailed, powerful yet pragmatic report delivered within very tight timescales, that drew on the lived experiences of service users and acknowledged the many voices who have a stake in the reform of mental health services. However, despite our commitment to involving service users, we also failed to provide appropriate support to a member of the research team and had to overcome substantial difficulties in arranging appropriate

#### Figure 4 - Barriers to user involvement

1. First and foremost, studies highlight a widespread lack of information for service users. This includes a lack of information about the nature of people's mental health problems, the side-effects of medication, alternative forms of treatment, mental health law and a range of other issues. Clearly, accessible information is an essential prerequisite for meaningful involvement and there will be little scope for progress until users are enabled to make informed choices about existing provision.
2. User involvement, if done properly, can be expensive and time consuming (for example, taking time to involve service users in decisions, producing accessible information, working with people rather than for them, paying users for their contributions etc.) - in the short term, these costs may seem prohibitive and agencies may not be prepared to invest in user involvement.
3. Existing mechanisms for involving service users in their own care may be limited in terms of their effectiveness. In particular, a number of commentators raise doubts about the extent to which users are routinely involved in developing their own care plans in conjunction with mental health practitioners and cast doubt on the accessibility of formal complaints procedures.
4. Professionals wishing to promote user involvement frequently express concerns about the 'representativeness' of individual service users, sometimes suggesting that particular users may be 'too well', 'too articulate' or 'too vocal' to represent the views of users more generally. While it is important that all users with views to contribute feel able to become more involved, a number of commentators emphasise the danger that the concept of 'representativeness' can be used as a sub-conscious method of resisting user involvement. As Lindow (1999: 166) responds:

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

*We ask how representative are they, and the others on the committee? We point out that as they are selected for their expertise and experience, so are we. Indeed, we are more likely to have been selected by a group than they are. We ask, would workers send their least articulate colleague to represent their views, or the least confident nurse to negotiate for a change in conditions?*

*We ask, if a person's criticisms are valid, what relevance has representativeness?*

*We point out that it is very rude to suggest that someone is not a 'proper' service user (that is, so disempowered and/or medicated that they cannot speak). We could ask, but do not, that the challenger produce his or her credentials, their certificates of qualification."*

5. Many mental health services may not be conducive to user involvement. For some people, mental health services can be experienced as extremely disempowering, with users being compulsorily admitted to hospital and medicated against their will. Users' contributions may also be discounted as a result of their illness or of public attitudes about risk and dangerousness.
6. User groups seeking to campaign for more responsive services often face a range of practical difficulties, such as financial insecurity and a lack of training.
7. Some workers may find it difficult to view service users as experts and resist moves towards greater user involvement.

(Glasby *et al.*, 2003b)

payment at a level which did not compromise welfare rights entitlements (see figure 5 for a summary of key lessons). On a more positive note, two years on, we are still collaborating on various projects, including research bids and articles/

dissemination such as the current paper. Perhaps this is one of the key lessons from *Cases for Change*: the importance of trying to do the right thing, learning from mistakes and trying to do it better next time.

### Figure 5 - Key lessons about user involvement in research

- Having a service user as a core part of the research team ensures a user perspective is included in every aspect of the research.
- There is no single ‘right answer’ - rather a series of different stakeholders with different views about how best to reform mental health services. This makes it all the more important that a user perspective is included in these debates.
- Researching alongside service users can challenge the assumptions, language and attitudes of other research team members - as health and social care professionals, two out of three of the main researchers in this study have worked in agencies that have contributed (directly or indirectly) to the negative experiences of the third team member.
- User involvement can support service users to return to work, develop new skills and boost confidence and self-esteem.
- Do not employ a single service user as a researcher - having more than one user on the team gives greater scope for peer support and helps spread the workload.
- Do not employ a single service user as a researcher - having more than one user on the team gives greater scope for peer support and helps spread the workload.
- Ensure that everyone involved in the study is aware of the importance of user involvement and committed to it. This includes members of the expert panel as well as support services such as pay roll and human resources.
- Seek financial/welfare rights advice before starting so that payments to user researchers do not damage the benefits they may be receiving.
- Above all, keep talking and keep trying – user involvement is difficult and we do not always get it right, but the benefits far outweigh the limitations and meaningful involvement in research is something worth striving for.

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