

User and carer involvement in mental health training

Gill Livingston & Claudia Cooper

Abstract National policy in the UK emphasises the importance of involving service users and caregivers in all types of mental health provision. The training of mental health care and social service professionals has always relied on seeing patients, but the patients' role has usually been a passive one. This is now changing, and service users and carers are becoming active educators in professional training, benefiting both the teachers and those taught. Provision is still very variable and is dependent on local initiatives. Voluntary organisations are active in this field, and there are now two academic posts for service users in the UK. This article explores the current forms of service user training, its benefits and drawbacks, and makes recommendations for future work.

Recent national policy has emphasised the importance of user and carer involvement in mental health services at a variety of levels (e.g. Department of Health, 2001). The National Service Framework for Mental Health states that 'Service users and carers should be involved in planning, providing and evaluating training for all health care professionals' (Department of Health, 1999). The Patients' Forum, INVOLVE (formerly Consumers in NHS Research) and the Commission for Patient and Public Involvement in Health all exist to ensure that patients and carers are involved with both the academic and the clinical side of health care.

In this article we review the benefits and drawbacks of service users' and carers' involvement in health education in general. We go on to consider their role in mental health education at different levels, and present some of the views of service users. Finally, we consider the practical implications for mental health training.

What to call 'users' and 'carers'

When invited to contribute this article, we found the terms used in its title contentious. As doctors we are used to thinking of the people we see for assessment and management as 'patients'. We know that colleagues in social work talk about 'clients'

and that other colleagues and managers talk of 'users', 'consumers' and 'stakeholders'. McGuire-Snieckus *et al* (2003) found that when people consult general practitioners and psychiatrists they prefer to be referred to as patients (as opposed to clients or service users) and they are happy for other health and social service personnel to call them either patients or clients, but 10% or less like to be called service users.

People acting outside the traditional role of receiving care describe themselves with a variety of terms. One group felt the term 'consumer academic' best reflected the range of responsibilities of a new academic user role, which included teaching and research (Happell *et al*, 2002). The Alzheimer's Society talks about 'carers' and 'family caregivers'. Mind (the National Association for Mental Health) talks about 'service users'. The Distress Awareness Training Agency (DATA) refer to 'resisters', 'survivors', 'users' and 'ex-users'. The mental health organisation SANE talks about 'sufferers, families and friends'. Another term we found was 'patient activist'. These different names reflect different views of the roles that we talk about in this article. When we use any of these terms here, we use either the word that the people concerned used for themselves, or one of the words listed above as being synonymous with 'user' or 'carer'.

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The debate about user and carer involvement in education

The stakeholder approach, which involves consumers as active educators, contrasts with traditional methods of clinical training and education. Health and social care professionals have usually been trained through a combined academic and apprenticeship system. Doctors, nurses, occupational therapists, social workers and psychologists have all worked, both as students and specialist trainees, with qualified professionals; they have all been trained in patient care in clinical settings, often at the bedside or within clinics and general practitioners' surgeries. Thus, patients have always been involved in the education of professionals, but usually in a passive role. In this traditional style of teaching, patients are simply regarded as the ones who have the symptoms. This role is now being considered more critically. There has always been a theoretical requirement for patients to be given a choice about whether they become involved in training, when they present asking for help; there is concern, however, that such choice rarely exists in practice, and that patients are being exploited to educate health professionals.

Countering this concern, some users and carers have pointed out that they have a unique understanding of their own illness and the experience of being in the health care system. They feel that they could and should play an active part in teaching. There is increasing recognition that users can usefully contribute to teaching in a more active role, as 'experts' in their illness, with involvement in decisions about what is taught, in assessment of the learning taking place and in research evaluating teaching programmes (Spencer *et al*, 2000; Roper, 2003). Training, practice and research usually define expertise. The patients' expertise is defined by experience, and this different perspective gives them a unique role in teaching. Patients who teach are often unrepresentative of the majority of patients, because they have by definition an interest in becoming involved in ensuring that others have what they regard as good treatment from health professionals.

Patients or actors? The move away from using patients to educate

There is a tension between two different models of training. One prioritises the need to standardise, so that all learners see the same range and pattern of illnesses. The other emphasises the need to see real patients who react in an unstandardised way.

Using actual patients within an examination setting leads to the possibility that assessment may be unreliable, because different students will see different patients with a variety of symptoms, presentations and willingness to engage. One study compared standardised and real patients in terms of reliability as a test of clinical competence in a final-year qualifying undergraduate clinical examination (Wass *et al*, 2001). The history-taking was observed uninterrupted, and the students were asked questions during a structured presentation. The conclusion was that the use of 'long cases' was

Box 1 Views of patients taking part in medical student examinations

- 'I've come for the last few years. I think it's important that students are tested on actual patients – how else are they going to get used to talking to real people?'
- 'It's good for them to get used to hearing from the horse's mouth, so to speak; it might mean they're less likely to turn into textbook doctors. I had a textbook doctor in prison – he'd read that you only got the shakes for a week after stopping heroin, he had no idea what goes on – I had to get my wife to bring the gear in.'
- 'It was nice, it's a good chance to talk to someone about how I'm feeling.'
- 'I think it's a good thing to do, and I found it interesting, but maybe a few months ago when I was much more ill I would have found it too upsetting – perhaps you need to get a combination of actors and real patients, so actors can do the bits where people are very unwell . . . they need to understand how their decisions affect our lives.'
- 'I don't mind helping out, but it can be tough, very harrowing to go through the whole history, and I was worried about not remembering everything.'
- 'I don't see how doctors can qualify without being tested on how they talk to patients, I think it's essential, and it's for our benefit in the long run to have doctors who know about the illnesses we've got . . . I think the ones I've seen today will make good doctors.'
- 'I saw lots of medical students when I was an in-patient too – I think it's good that the training is "hands on".'
- 'Do you know of any other things like this going on – will you bear me in mind?'

neither more nor less reliable than using the objective standardised clinical examination (OSCE). Standardised simulated patients are now being used with increasing frequency to increase the reliability of examinations. In Part I of the examination to become a Member of the Royal College of Psychiatrists (MRCPsych), for example, the long case was replaced in 2002 by the OSCE. Similarly, at University College London (where we both teach medical students), 2003 was the last year in which patients participated in the final examinations; from this year onwards the examinations will use OSCEs. However, the decision that this is the only way to assess has not been made. The MRCPsych Part II examination will continue to use real patients for candidates to assess in the clinical section, and similarly students at UCL will continue to present long cases as part of their clinical assessment before the final examinations.

As we could not find any report about the opinion of patients participating in such examinations, we asked some of the patients taking part in the psychiatric long and short case assessments at UCL about their experiences (Box 1). These people felt that students needed to talk to real patients to develop their communication skills and understanding, as people's illnesses might not conform exactly to the textbook description. Most of the patients enjoyed the experience of being involved in the examinations, and one said that she found it therapeutic. There was concern that it might be upsetting to be interviewed if you were acutely unwell; however, another patient specified (without it being part of the interview) that he had found it a positive experience to talk to students while he was unwell.

It could be argued that the way to achieve homogeneity of training is to use actors who will present the same symptoms and responses to every candidate, or to use real patients only when teaching very large groups. The proponents of learning through seeing real patients in everyday clinical situations argue that this method has high validity, because students are trained in and tested on a skill they require for real life.

The role of patients as teachers in medical education

Interviews with patients suggest that they would like more active involvement, particularly in improving students' communication skills (Evans & Seabrook, 1994). Spencer *et al* (2000) describe a framework for increasing patient involvement in specific educational situations: for example, users could act as questioners, asking the student about their condition, and the student could spend time

Box 2 Teaching roles of patients in medical education

- Giving presentations
- Acting as a facilitator in seminars
- Demonstrating to small groups
- Providing personal tuition
- Giving feedback
- Assessing students
- Contributing to the evaluation of teaching programmes

researching these areas before reporting back to the patient. A systematic review of publications from 1970 to 2001 discussing the role of patients as active teachers identified only 23 articles (Wykurz & Kelly, 2002). Only one of these articles was related to mental health, and this was also the only one co-authored by a caregiver or patient (Butterworth & Livingston, 1999). Within the reported studies, teaching roles varied widely (Box 2). Some of the projects were designed to teach postgraduates, but most targeted undergraduates. A wide variety of topics were involved (Box 3). The patients were often given training for their role. All except one group found that teaching was a positive experience for both the teachers and the taught. Patients described themselves as experts in their own condition (Stacey & Spencer, 1999). They also found that they themselves had benefited (Box 4), through learning more about themselves, and through personal satisfaction, empowerment and increased confidence (Butterworth & Livingston, 1999; Stacey & Spencer, 1999).

Box 3 Topics covered in patient and carer teaching

- General physical examination
- Physical examination of one system or part of the body
- Communication skills
- Carer experience, e.g. how it feels to look after someone with dementia
- Patient experience, e.g. how it feels to be detained under a section of the Mental Health Act
- User involvement in evaluation and research
- Diagnostic skills
- Managing particular illnesses, e.g. cardiac disease, HIV infection, developmental disorders in children

Box 4 Benefits to carers and users of involvement in teaching

Involvement in teaching:

- allows people to learn more about themselves
- provides a sense of personal satisfaction
- empowers the individual
- increases confidence
- enables them to earn money
- provides a positive use for people's illness
- acknowledges their expertise
- improves their understanding of mental and social service staff
- offers an opportunity to help future patients

Another project, at Southampton University, involved medical students who together with nursing, social work, occupational therapy and physiotherapy students had joint monthly workshops with people caring for a terminally ill relative, or people who had been recently bereaved (Turner, 2000). The carers' role in these groups was to express their views of the value or otherwise of the services received, and what it was like to be a carer. Evaluations by both carers and students were positive. Carers highlighted the need for group reflection on each session after it had ended and requested more specific information about the sessions beforehand.

Evaluation of user-led training

Campbell (2000) commented that:

'There is almost no research on how service user involvement in training mental health workers is developing, so that although there are good service user trainers available, it is difficult to grasp a sense of direction.'

Simpson & House (2002), in a systematic review of user involvement in the delivery and evaluation of mental health services, found only two studies evaluating user-led training. Involving patients as teachers has important educational benefits for learners: not only does it allow the acquisition of skills, but also it can change attitudes positively. In a study in the USA (Cook *et al*, 1995), 57 mental health professionals participating in a 2-day course on delivering assertive case management services were randomly assigned to receiving the second day of training from either a user or a non-user. When attitudes were assessed following training, participants trained by a user were significantly more positive towards users generally, and showed greater awareness of stigmatising factors of mental illness. There was no difference in the two groups'

judgements of the likelihood that service users would recover and become productive citizens. In a second study (Wood & Wilson-Barnett, 1999), nursing students who had had more and earlier exposure to user involvement showed more empathy, used less jargon and had a more individualised approach to patients.

Teaching medical students

Patients' attitudes to involvement in traditional teaching when students have clerked and observed psychiatric patients have been reported as very positive (Evans & Seabrook, 1994; Coleman & Murray, 2002). Walters *et al* (2003) conducted a questionnaire and in-depth interview study with patients, medical students and general practitioner tutors involved in a teaching programme. The general practitioner recruited patients who were currently well, and asked them to agree to a student interviewing them (usually in their own home), specifically for the patient to teach the student about psychiatric illness and the process of recovery. All groups interviewed suggested that there were direct benefits to the patients taking part, such as empowerment and raised self-esteem. A few patients found the interviews distressing, and research is needed to identify characteristics that would allow patients who might be distressed to be distinguished from those who would benefit.

This project is in line with the views of a patient activist who wrote to the *BMJ* to say that patients with mental illnesses are ideally suited to be teachers, as psychiatric diagnoses are based on what patients experience, as opposed to laboratory and radiological investigations (Nil, 2002). The writer suggested that as students meet only very unwell patients in hospital settings with, in particular, acute psychoses, they develop a pessimistic and unrealistic view of mental illness. If students met patients who had recovered, they would understand the disease better and this might encourage them to become psychiatrists. The present system of seeing extremely ill patients may be discouraging and lead to therapeutic nihilism.

In another project, which explored patients' views of their involvement in teaching, psychiatric patients employed in a protected workshop were interviewed twice by two medical students (Greenberg & Cohen, 2003). The second interview sometimes took place at the patient's home, and a carer was invited to attend where appropriate. The students presented their findings at a case conference, attended by the patient and (if the patient consented) the carer. After the presentation, both the patient and the student were asked what they thought of the interview and specifically how they felt about the patient being

present at the case conference. Most comments from both patients and students were positive. Negative comments by students centred on the presence of the patient at the conference, which they felt was embarrassing or confusing for the patient. Some patients agreed with this, although many found the experience interesting and commented that it was not upsetting. Negative comments by the patients about the interviews most commonly reflected a cultural gap. The study took place in Israel, and there were, for example, male patients who felt uncomfortable being interviewed by women. In addition, many of the students were not dressed as modestly as ultra-orthodox tradition dictates. The authors suggested that more careful preparatory discussions with patients before the interviews could avoid such problems. We think that perhaps the students also needed more preparation.

A group of carers of people with dementia have participated in the formal lecture programme for undergraduate medical students at the Royal Free and University College Medical School since 1995 (Butterworth & Livingston, 1999). After a lecture on dementia, one of the carers acts as a facilitator and questions three other carers about aspects of the caring role, and the successes and failures of services. The facilitator's personal knowledge of the other carers makes it easier to ask personal and intimate questions than would be the case with an unfamiliar interviewer. The facilitator then asks the students if they have an experience in their own family of caring for someone with dementia, and the answer is often in the affirmative. The students rated the session highly on measures of clarity, interest and relevance. The authors, one of whom is a carer who has participated in the programme, comment that the carers were initially tentative when asked to participate, and felt unsure about whether they had anything useful to say. As well as being beneficial for the students, the sessions might have enabled carers to feel for the first time that their personal caring experiences have a general meaning and value; realising that they have something to contribute to training might in itself be therapeutic.

Training psychiatrists

Faulkner & Thomas (2002) suggest that:

'Psychiatrists should attach as much importance to user-led research in the processes of clinical decision-making as they do to randomised controlled trials. This has implications for continuing professional development and the training of psychiatrists.'

There are now many examples of high-quality user-led research (Faulkner & Thomas, 2002; Rose *et al*, 2003). Two members of the Service Users

Research Enterprise recently presented results of their descriptive systematic review of patients' perceptions of electroconvulsive therapy (ECT) at the Royal College of Psychiatrists' annual conference in 2003. This research had previously been published in the *BMJ* and influenced the National Institute for Clinical Excellence policy on ECT (Rose *et al*, 2003). This group of users has thus influenced guidelines and policy. The dissemination of user-led research findings through journal publications and presentations is an important way in which users can influence the training and continuing professional development of psychiatrists.

User groups are also becoming involved in the education of psychiatry trainees. Ikkos (2003) described a basic clinical interview skills workshop for new trainees, consisting of weekly sessions for 6 months, to which users have been contributing since 1999. The users lead sessions in which trainees are invited to consider what expectations patients might have of them, how patients might feel as they approach a psychiatric interview, and how the trainees' feelings might affect their own conduct in the interview. The users also make active contributions to other sessions through observations and comments in discussions and role-play, although they do not take roles themselves.

Trainees were asked to complete a feedback questionnaire. Perceived benefits were felt to be increased empathy, as well as an appreciation that patients are able to play an active part in decision-making, and that they have active memories of their treatment during a psychotic episode. A number of students indicated that they would have liked the users to be involved in the role-play exercises, and Ikkos reports that the user group are currently piloting this. Some trainees, however, appeared to find the user participation threatening and insensitive to their own emotional needs, and to feel that the users involved emphasised their own agenda and forgot that the sessions were a training programme. Users involved gave persistently positive feedback about the sessions. Overall, the initiative was felt to be beneficial, particularly in helping the training scheme to meet the Royal College of Psychiatrists' (2004) psychotherapy training guidelines relating to interview skills. Ikkos comments that the findings complement those of an earlier report that patients can successfully contribute to psychiatric training through lecturing on an MRCPsych course (Crawford & Davies, 1998).

Employing users as teachers

The entitlement of users who have teaching and research roles in the health service to receive the same pay, benefits and status as other mental health

teachers has been highlighted (Happell *et al.*, 2002; Coldham, 2003). We know of only two user academic teaching and research posts at UK universities: the first of these is at the Institute of Psychiatry, where teaching commitments include the MSc courses in health services research, community mental Health and social work. Sessions mainly focus on user involvement in evaluation and research work (Rose, 2003). In the second post, a mental health user consultant has been appointed as a visiting lecturer to four universities (Coldham, 2003).

A centre in Australia employs a 'consumer academic', a user with a remit including teaching postgraduate psychiatric nursing students. The views of 25 postgraduate nursing students were solicited on the first day of a course about the involvement of users in mental health services and, in particular, about the post of consumer academic (Happell *et al.*, 2002). Although those interviewed were generally supportive of the involvement of users in planning their own treatment and in the planning of mental health services, the majority of respondents disagreed that users should be involved in the planning and delivery of all staff education and professional development. The authors of the study argue that, although the value of increased user participation in provision of mental health services has been clearly demonstrated, education and training are needed if mental health professionals are to adapt to the changing role of the user and this more collaborative approach. We think that this may not be a justified conclusion, as the question specified the involvement of users and carers in all education and professional development. The respondents may be enthusiastic about user involvement but feel that it is not essential to have user involvement in every learning situation.

The use of patients as active teachers also raises issues of appropriate training and standards. Universities are now required to ensure that teaching is of an appropriate standard, that there is feedback from the students, which is acted upon, as well as peer review. There seems to be no literature on what is necessary to ensure that user and carer educators have an appropriate standard of objectivity and communication skills. It could perhaps be argued that this does not matter, and that because users are relating their own experiences, objectivity is less important. We do not agree that skill in either form or content is irrelevant. Clearly, all teachers have to be able to communicate or nothing is learned. If content is inaccurate, it can be misleading; if it is extremely negative, students may be left feeling hopeless rather than with increased sensitivity or understanding. The next stage in development of this form of teaching should be consideration of training and quality control. The user perspective is

becoming increasingly important in approved social worker (ASW) training. Two survivors of the mental health system have written a guide for service users taking part in ASW training (Hastings & Crepaz-Keay, 1995). It gives advice to users about how to negotiate their role, how to plan sessions, and how to cope with difficult situations such as hostility or defensiveness from ASWs who might feel threatened by the user in an educating role. It also discusses the benefits and potential disadvantages of users revealing their personal histories in the sessions.

Mental health voluntary organisations employ users as trainers. One of these is DATA, a user organisation based in north-west England, which was established in 1988. This organisation has provided trainers for groups, including student nurses and social workers, on subjects such as user and carer involvement in services, the ethics of secure mental health services, mental health promotion, users and carers and the National Service Framework for Mental Health, and reform of the Mental Health Act. The organisation also took part in planning and staff training for a project at Ashworth High Security Hospital aimed at improving patient participation and involvement (A. Hughes, personal communication, 2003). The organisation Mind runs a range of courses, which in 2003 included 'Making sense of voices'; targeted at psychiatrists, psychologists, community mental health workers and keyworkers, this focused on the experience of hearing voices from the viewpoint of 'voice hearers' (Mind, 2003).

A number of mental health organisations (e.g. Mind and DATA) run courses that equip users to become more involved in services, including the training of professionals in user issues. The NHS Executive Mental Health Task Force User Group (1994) has produced a training pack for service users working as trainers, speakers and workshop facilitators.

Although the National Service Framework for Mental Health states that health and social services should 'promote mental health for all, working with individuals and communities' (Department of Health, 1999), doubts have been expressed about how this could currently be managed by statutory services without further resources (Deahl *et al.*, 2000). User organisations have a major role in health promotion, and this includes running training courses for primary care staff, and for other workers outside mental health services who are likely to come into contact with people with mental health problems. Topics covered by these courses include listening and counselling skills for non-specialists, mental health issues relevant to the workplace, and mental health awareness (for further information go to http://www.sane.org.uk/SANE_Services/Training.htm). Mind runs courses about the Mental

Health Act, targeted at advocates, voluntary sector advisers and lawyers with an interest in mental health issues (<http://www.mind.org.uk/Information/Conference+and+training/>).

Involvement of ethnic minority groups

We could find no published study specifically relating to the involvement in mental health training of users and carers from ethnic minority groups, although a number of authors have written about the need to involve people from these groups in culture awareness training. Sachdev (2001) described involvement of the Maori community in cultural training of mental health workers in New Zealand, and concluded that:

'the primary initiative has to come from the minority community itself, and that sociopolitical conditions have to be created for the change to occur.'

In the UK, the Royal College of Psychiatrists has outlined plans to involve Black and ethnic minority users and carers in the development of a cultural capability training manual, for use as part of the MRCPsych education programme and CPD (Royal College of Psychiatrists, 2002). Diverse Minds is a policy unit set up by Mind in 1997 with support from the Department of Health. It aims to make mental health services more responsive to the needs of people from Black and minority ethnic communities. The unit has developed, piloted and facilitated training courses in racial, cultural and mental health awareness, and organised several conferences to promote dialogue between service planners and Black and minority ethnic communities.

The future of user training

National policy is increasingly emphasising the importance of involving service users and caregivers in all types of mental health provision. Within the field of mental health training, patients have usually been given a passive role. This is changing at last, and service users and carers are becoming active educators at different stages of professional training – both undergraduate and postgraduate – benefiting both teachers and those taught. The literature on the subject is limited, but by approaching service user organisations directly we found many initiatives. Provision is still variable, however, and dependent on local action. The voluntary organisations are leading proponents of this development. It is encouraging that there are now two academic posts for service users in the UK.

Despite the considerable potential for systematic development of the role of service users and carers in the fields in which it has been shown to be efficacious, there has been some resistance from professional groups to this process. Evaluation has, however, indicated that service user involvement in training has a positive impact. There is a need for further research to identify patients who might be distressed by involvement in teaching, to define the characteristics of successful service user training in mental health and to ascertain the impact of service user training on medical students' attitude and skills. One author has suggested that teaching by service users could increase recruitment in understaffed specialties, and this would certainly be an interesting idea to explore. The question of which patients are vulnerable to the relatively rare distress associated with being an educator is particularly important for individual clinicians and service users considering new involvement in teaching. In addition, there is a need to improve the training of service users and carers as educators and to evaluate their teaching in line with that of other health service educators.

In conclusion, involvement of users and carers in mental health training is a beneficial development for service users and professionals, but one that requires further work.

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- d be less stigmatising of users
- e usually rate training experiences negatively.

2 Service users report the following benefits from teaching:

- a empowerment
- b less use of benzodiazepines
- c decreased need for contact with services
- d better understanding of mental health professionals
- e personal satisfaction.

3 When involving service users in training, it is important to:

- a decide whether the user will have equity in terms of pay with the professionals who are teaching
- b establish that the user has professional teaching qualifications
- c ensure that the user will not say anything that disagrees with evidence-based teaching
- d ensure that feedback on teaching is given to the service user
- e investigate what support and training is available.

4 Further research is needed:

- a to identify patients who might be distressed by involvement in teaching
- b to determine if service user teaching has any place in psychiatry
- c to ascertain the characteristics of successful service user training in mental health
- d to find out whether teaching by service users could increase recruitment in understaffed specialties
- e to ascertain the impact of service user training on medical students' attitudes and skills.

5 Voluntary organisations are involved in mental health training through:

- a training student nurses
- b increasing patient involvement in special hospitals
- c setting extended matching items for the MRCPsych examinations
- d explaining the experience of auditory hallucinations to professionals
- e teaching social workers about the reform of the Mental Health Act.

Multiple choice questions

1 Training by service users leads mental health professionals to:

- a have more positive attitudes towards service users
- b use less jargon
- c be more optimistic about patients' recovery

MCQ answers

1	2	3	4	5
a T	a T	a T	a T	a T
b T	b F	b F	b F	b T
c F	c F	c F	c F	c F
d T	d T	d T	d T	d T
e F	e T	e T	e T	e T