A good practice guide

Learning from Experience

Involving service users and carers in mental health education and training

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Executive Summary

If service delivery is to be characterised by an ethos of partnership, then such partnerships must also form the foundation of mental health education. By virtue of their direct experience of mental distress and of professional responses (helpful and unhelpful), service users and carers have valuable knowledge and expertise to offer. Their involvement has the capacity to enrich the learning of students, offering a more stimulating and challenging educational experience – and one which can equip students to practise more effectively.

Many courses are keen to progress with service user and carer involvement, although sometimes at the early stages of the process. Increasingly, this is something that will be expected by professional bodies and commissioners, as national strategies such as the Ten Essential Shared Capabilities are rolled out across the mental health workforce.

Effective progress requires a broad strategy to involve service users and carers in all aspects of the educational process (not just coming in for one or two teaching sessions). This may involve Service users and carers in:

- direct delivery of learning and teaching
- course / module planning
- programme management
- recruitment and selection of students
- practice learning
- student assessment
- course evaluation
- joining courses as participants

Achieving meaningful involvement depends on:

1. establishing a culture which considers the viewpoints and contributions of service users and carers to be of equal value to academic and professional perspectives
2. developing an infrastructure to recruit, support and give training to service users and carers
3. paying service users and carers at a fair rate and in ways that do not undermine their financial security
4. valuing and encouraging diversity: making sure that minority experiences and viewpoints are included
5. having a strategy for taking forward involvement that is supported by management, professional bodies and other key stakeholders. This must include appropriate funding.

The Guide contains a general introduction to the topic and, drawing on a range of current initiatives, pointers towards good practice in relation to each of the components of effective involvement. A range of evaluation tools are offered which may be useful in charting progress and identifying the next steps to be taken.

How to use the guide

This Guide aims to be comprehensive and contains some general discussion and background information, some specific tips and ideas, and a range of examples of current practice. Other examples and related documents will be made available on the Mental Health in Higher Education website: www.mhhe.ltsn.ac.uk, where you can also log examples of your own.

In order to gain an overview of the topic, some readers may find it helpful to read the Guide from start to finish. However, we expect that many will use the Guide for reference, either individually or within teams, and will dip in to particular sections as and when required. Pointers to good practice are highlighted for ease of reference.

Readers who are using the Guide as a companion to the National Continuous Quality Improvement Tool for Mental Health Education may prefer to start with Section 5 and then refer back to those Sections which explain particular points in more detail.

1 Introduction

1.1 Purpose of the Guide

Achieving meaningful involvement of service users and carers is a journey of discovery. There is no 'one size fits all' model that will work for all programmes in all localities. What works for a particular course will emerge out of commitment, dialogue and hard work by teaching staff, service users and carers. We hope that this Guide may provide some useful pointers to make this process easier.

Some programmes have yet to start the journey and are looking to see what might be the most appropriate first step for them. Others may have started down the road and be keen to do more than simply invite service users and carers along for a one hour 'user' or 'carer' slot each year. It is increasingly recognised that service users and carers can and should be involved in all aspects of planning, delivering, assessing and evaluating mental health education and training.

This Guide seeks to build on the experience gained so far by a wide range of programmes, on recent research conducted in conjunction with Suresearch (Tew et al, 2003) and Carers in Partnership (2004), and on guidance developed for the training of Primary Care Graduate Mental Health Workers (Gell, 2003). Whilst intended to be comprehensive, it recognises that practice in this area will continue to evolve. There is scope for further work, in particular around the involvement of service users and carers from Black and Minority Ethnic groups; and other currently underrepresented groups such as young people and older service users and carers and those who are in touch with primary care services. Further thought needs to be given to the issues raised where education is delivered in interdisciplinary contexts. It is hoped that others will take this guidance as a starting point, refine and build on it.

1.2 Who is the Guide for?

This Guide is first of all intended for lecturers and course directors in UK higher education with involvement in either pre- or post-qualification courses in the following areas:

- nursing and professions allied to medicine, including occupational therapy and physiotherapy
- social work
- psychology
- medicine and psychiatry
- Primary Care Graduate Mental Health Workers and other new designations of mental health workers
- interprofessional programmes and professionally non-affiliated programmes such as the Certificate in Mental Health Work.

Beyond this, it is hoped that the Guide will also be a valuable tool for all those who play a part in making user and carer involvement in mental health education a reality, in particular:

- users of mental health services
- carers
- lecturers and course directors in other subject areas within higher education
- trainers and managers in Trusts, local authorities and non-statutory organisations who provide accredited in-house mental health training programmes
- commissioners of mental health education and training (such as Workforce Development Confederations/ Strategic Health Authorities)
- NIMHE Regional Development Centres

While it is not specifically targeted at workplace-based NVQ / SVQ, induction or other such training, it may nevertheless have some relevance in these contexts.

1.3 Link with the National Continuous Quality Improvement Tool

While it is hoped that this Guide will be a valuable point of reference in its own right, it has also been designed specifically to accompany the National Continuous Quality Improvement Tool for Mental Health Education (NCMH, 2003). This provides a mechanism for programmes to review their mental health teaching.

It was developed by the Northern Centre for Mental Health with support from the NIMHE National Workforce Programme, in response to a national mapping exercise of mental health education and training which found that:

- mental health education tended not to be linked to the national policy agenda
- service user and carer involvement, at all levels, was not generally established
- there was variation in the assessment of the impact of training.

Although the Quality Improvement Tool covers a number of aspects of performance, user and carer involvement is seen as central if students are to learn the values, knowledge and skills that are most relevant to practice.

Where it is being rolled out to higher education programmes it has the potential to be used as a lever for change - both internally, to help overcome barriers within education provider organisations, and externally to promote productive dialogue between providers and stakeholders such as service user or carer groups and Workforce Development Confederations/ Strategic Health Authorities. It is hoped that the Quality Improvement Tool will become integrated into routine quality enhancement processes, and its use be reviewed in the regular Developmental Engagements undertaken by the Quality Assurance Agency.

1.4 Language and terminology

There are variations, across different settings and disciplines, in the language conventionally used; and people may be more comfortable with some terms rather than others. For the purposes of this Guide, the term 'mental health' is taken to refer to a state of mental wellbeing, and 'mental distress' is used to refer to a significant departure from this state. The term 'service user' is used to denote clients, patients, survivors or people with lived experience of mental distress, and the term 'carer' is used to denote relatives or friends who play an important role in supporting people experiencing mental health difficulties. The term 'student' is used to denote people who are receiving education or training, whether at pre- or post-qualification level, in-service or within an academic institution. The term 'teaching staff' is used for lecturers, trainers, practitioners or others who are regularly involved in the organisation and delivery of education or training. We do however recognise that people's roles can overlap – students and teaching staff may also be service users or carers. The term 'practice' is used to denote direct work with service users or carers.

Some terms, such as 'Approved Social Worker', may be specific to the legal or service context of particular countries within the UK. For the sake of clarity, alternative terms are not included in the text. However, the educational issues, and the practical issues to do with making progress in service user or carer involvement, are likely to be very similar across the UK.

1.5 Service users and carers: commonalities and differences of experience

In the development of this Guide, soundings were taken among groups of service users and carers who had experience of involvement in education and training. People were asked whether they felt it would be best to have a combined guide, or separate documents dealing with the participation of service users on the one hand and carers on the other. The overwhelming response was that, as there were many more experiences of commonality than difference, a combined guide would work better. Nevertheless, service users and carers may have genuine differences in perspective, and this need to be acknowledged within the educational process (see Section 2.7).

Service user and carer involvement in education and training has evolved at different rates. There are currently more examples of good practice relating to service user than to carer involvement. It is hoped that this disparity will diminish in the future as programmes look to developing service user and carer involvement, together and in parallel, as part of a single strategy

2 Setting the Scene

In this section we outline the training routes for mental health professionals in higher education. We consider, from a range of perspectives, the arguments for involving service users and carers in mental health education. Finally, we discuss how carer and service user perspectives may be seen as distinct and complementary.

2.1 How do students learn about mental health?

Many students first learn about mental health within vocationally oriented academic programmes located within universities and colleges that offer higher education level programmes. These typically lead to an academic qualification (Diploma in Higher Education, undergraduate or postgraduate degree) and an award from or registration by a professional body (e.g. Nursing and Midwifery Council, General Medical Council, General Social Care Council).

Typically, such programmes include a taught academic element and an element of direct practice, and students have to achieve specified standards in both elements in order to obtain their qualification. Many programmes are delivered in some form of partnership with Trusts, local authorities and other providers of mental health services that offer the settings for the practice element of the programmes.

Within most current forms of qualification training, mental health is part of a broader generic programme (for example, qualifying level training in medicine, occupational therapy, physiotherapy, clinical psychology or social work). Mental health may constitute a designated specialist pathway (as in pre-registration nursing), or may be taught as a specific module or sequence undertaken by all students.

Once qualified (as a doctor, social worker etc.), many students will undertake accredited post-qualification training that is specific to mental health – and increasingly these courses may be organised on an interprofessional basis. These programmes may be located within Higher Education Institutions, or in people's workplaces (e.g. Trusts or local authorities), but generally involve some form of partnership between the two in order to provide an appropriate mix of academic and practice input, and to provide a further qualification that is accredited both academically and by relevant professional bodies.

An exception to this training route is psychology, where students complete an undergraduate degree which generally has no practice element, and then obtain relevant practice experience; before proceeding to a postgraduate course in clinical psychology, which contains both academic and practice elements and leads to the recognised professional qualification.

Recently, with the goal of broadening the mental health workforce, new designations of worker have been developed (Primary Care Graduate Mental Health Worker; Support, Time and Recovery Worker, etc). A variety of training routes for these workers are being established, which may involve some form of part-time university or college based learning together with assessed practice in their workplace.

Changing service context and value base

The National Service Framework for Mental Health proposes that "service users … should be involved in planning, providing and evaluating education and training" (DoH, 1999, p.109). This reflects a fundamental shift in the culture of mental health services. There has been a tendency to reproduce a division between 'us' and 'them', in which it is assumed that practitioners, educators and students are somehow different from people with direct personal experience of mental distress, either as service users or as carers. Professional education has been founded on a value base which assumed that practitioners needed to be 'experts' who imposed their frames of understanding and their methods of intervention upon service users and carers who, almost by definition, were seen as lacking insight or capacity to discover their own solutions.

Within the current culture of mental health provision, a different value base is emerging, based on principles of partnership between practitioners, service users and carers (see NIMHE Cases for Change, 2003). Each is seen as being able to offer their own valuable contribution in terms of developing a more holistic understanding of mental distress and its impact, and as having the potential to be actively involved in working towards recovery.

If service delivery is to be characterised by an ethos of partnership which values the expertise of service users and carers, then it is becoming increasingly recognised that such partnerships must also form the foundation of mental health education. Working in Partnership appears as the first of theTen Essential Shared Capabilities that have been set out by the National Institute for Mental Health in England as the underpinning framework for the training of the whole mental health workforce (Hope, 2004).

In making ideas of partnership a reality for students, the medium must be congruent with the message: it is the process of education that is likely to be more powerful than its content in shaping the attitudes and capabilities of the practitioners of the future.

Knowledge and skills

The potential educational benefits of service user and carer involvement may go beyond instilling a value base of mutual respect and partnership. Through their direct experience of living with mental distress, and increasingly through their active involvement in research, users and carers are developing a knowledge base of immediate relevance to mental health practice.

At times, this may be complementary to the knowledge base that is currently taught – for example suggesting additional dimensions to an assessment so that it encompasses the fullness of a person's life, recognises strengths and highlights issues that may make a major difference between being able to keep well or suffering some form of relapse.

At other times, user and carer knowledges may be challenging of existing 'professional' orthodoxies and the power bases that uphold them. For example, service user trainers may wish to promote alternative survivor movement models to shed light on mental distress, increase understanding of risk and promote recovery. Entering into these debates within an ethos of mutual respect may be crucial in driving forward user-centred forms of professional practice. As Thomas and Bracken argue, in reflecting on their own training as psychiatrists: "Some of the knowledge we acquired during our training has been a hindrance. How we work clinically today evolved painfully and fortuitously … partly fired by the critical observations of service users" (1999, p.14).

As well as introducing their own perspectives, service users and carers can play a crucial role in helping to prioritise the most important areas of knowledge and understanding to focus on in a particular course. For example, in planning the training of the Primary Care Graduate Mental Health workers, service users identified what they saw as the key areas that students should cover. Many of these would be applicable to all mental health training (Gell, 2003).

Service users and carers have a unique contribution to make to training in core professional skills, such as listening, communication, empathy, advocacy and offering counselling or advice. Insufficient weight has in the past been given to these in professional training and, where they have been taught 'in the abstract' without direct guidance and feedback from service users and carers, students may fail to learn about what is of most importance in establishing therapeutic partnerships. The immediacy of input from service users and carers is likely to mean that students taught **by** users and carers will be equipped to work in a more effective or qualitatively different way than those taught **about** relating to users and carers.

Learning outcomes and service outcomes

Research into service effectiveness across the care sector has shown that the direct involvement of service users, both in individual decision making and in service planning, can result in improved service outcomes (see, for example, Carpenter and Sbaraini, 1997). Although research is currently less available on the longer term practice outcomes of involving service users and carers in students' education, it is likely that the same principles apply.

We would therefore expect such involvement to help to produce practitioners who are capable of delivering improved (and more relevant) outcomes for service users and carers - through working alongside them to identify problems and solutions, developing their capacity to manage mental health difficulties, and enabling them to chart their own journey towards recovery. However, unless innovations in education and training are mirrored by developmental support to the organisations in which the students undertake the practice element of their training, and in which they subsequently work, new capabilities may be lost because they are not used.

2.3 What do students think about it?

Research indicates that, when user and carer involvement is properly planned and supported, it can be very highly valued by students, some of whom describe their experiences in positively 'life-changing' terms. Sessions devised and led by user or carer trainers may be described as, at the very least, 'refreshing' and sometimes (perhaps somewhat to the chagrin of other teaching staff) as the best input of the entire course. Some specific comments include:

"You remember what they say and how they feel, and they say things that you would never have thought of... It is good that they pull you up and say "what about this?"

We learnt more from the service users than we did out of lessons as it was them saying how they felt, they spoke with such feeling and we really got to relate to them

This session has made me more aware about the sort of nurse I would like to become in the future

It taught me to value other (different) people in a deeper way than before – understanding this emotionally rather than just intellectually"

2.4 What is in it for teaching staff?

Developing effective forms of service user and carer involvement is not easy, especially if this has to be done on top of one's existing work commitments. It takes time, not least to build good working relationships with users and carers. It requires a willingness to look again at course philosophies, teaching methods and learning and assessment strategies. Also it requires a humility that allows teaching staff to give up any vestiges of a superior 'expert' status based on 'knowing best'.

Inevitably, engaging with such changes can feel risky and there can be anxieties that things could go badly wrong, perhaps affecting the credibility of the course, or adversely impacting on the mental health of contributors. There may be concerns about contributors having a particular 'axe to grind'. However, experience has shown that, as long as service user and carer involvement is properly planned and supported (see Section 4), such fears have not been borne out in practice (Tew et al, 2003).

In fact, the pay-offs for teaching staff can be considerable in terms of job satisfaction and professional development. Different perspectives and ways of thinking can inject new life into course content that may have become rather boring and repetitive. Staff who no longer hold on to a practitioner role may find themselves much more in touch with current issues in mental health services; and this may address some of the issues raised in a recent report on lecturers' clinical activity (Ferguson et al, 2003). Teaching staff may learn new knowledge, skills and ideas from the service users and carers with whom they are working, and benefit from ongoing and constructive challenges to their value base. They may also discover that service user and carer colleagues are able to offer personal and professional support which differs from that received from other teaching colleagues.

In such ways, partnership working can be revitalising, stimulating and supportive – just as it can be for practitioners who are able to adopt this approach in their practice:

> *'It has brought a new dimension to my own teaching, greatly enhanced the students' learning experience and I myself have learned more from working with user and carer trainers than I can easily express*

> It makes it feel more like it is not just them and us, and that we are trying to work together'

2.5 What is in it for service users and carers?

Service users and carers may wish to become involved in the field of education for a wide variety of reasons. For some, it may be a case of wanting to give something back, in recognition of what they feel they have received from services. Others may wish to tell their story to a wider audience. This may arise out of a positive experience of services or, conversely, repeated experiences of not being able to tell their story within the services that were supposed to be there for them. Others may be motivated by a desire to bring about change in professional practice, so as to improve the quality of services that they and others receive in the future.

Taking on a positively valued role in education and training may contribute to a person's self-esteem, enhancing their process of recovery and / or capacity to support others (Masters et al, 2002 p.312). Dialogues with peer educators may lead service users and carers to have a better appreciation of professional perspectives (as well as the other way around): a deeper, more balanced and understanding doctor-patient relationship was seen to result from research into user involvement in the teaching of undergraduate psychiatry (Walters et al, 2003).

For some people, involvement may provide a starting point towards ongoing employment (and perhaps qualification) either in the field of education, consultancy, or mental health service provision; or in the broader world of work. (Re)entering employment is a key priority for many service users, and evidence shows that it can be positively beneficial for those with long-term mental health problems – particularly where this can be flexibly tailored to their level of capacity at a given point in time (Sayce, 2000).

Some comments from service users and carers include:

This is the first time that having mental illness was an advantage

You said that this would not be a therapy group, but I have found it very therapeutic

It was a very rewarding experience and I would recommend it to anyone

It has been cathartic for me and part of my recovery; the chance to raise issues and get professionals to reassess their working and thinking from a service user point of view

I have valued being given an opportunity to have a voice as a carer

2.6 Implications for facilitating use of self in practice and education

In the past, people with personal experience of mental distress have faced discrimination when applying to mental health programmes as students, and for jobs in mental health services. This is slowly beginning to change; and now life experience, as either a service user or a carer, is beginning to be seen as valuable resource.

The explicit involvement of service users and carers in education can pave the way for both students and teaching staff to be more open about their own experiences, and for these to be valued and used as a resource within the learning process. In turn, this may enable the development of more effective and user-centred forms of practice. These issues are currently being explored by the Mental Health in Higher Education project.

2.7 Incorporating user and carer input as distinct and complementary perspectives

There can be a tendency for service user and carer perspectives to be 'lumped together' as if they were one and the same. In practice, there may be many areas where users and carers agree and share common experiences - but there are also other areas where their experiences and viewpoints may differ. Both users and carers tend to value those services and practitioners willing to work in partnership with them and value their strengths and knowledge about what works best in promoting or sustaining recovery. However, carers have needs in their own right, which can be overlooked by services. And service users may sometimes feel that carers take over too much.

Overall, many service users and carers would say that they have more issues in common than those that are different. Most are very willing to work collaboratively in education and training contexts, so long as they reserve the right to have their differences; and to use them to develop students' understanding.

Pointers towards good practice

- Right at the start, there should be an opportunity for joint planning between users and carers involved with a particular course or module - to identify areas where they may wish to work together and those in which they will 'agree to disagree'.
- Professional lecturers should not use potential for difference of perspective as a basis for 'divide and rule', or to impose their own agendas on what should be presented.
- There may need to be a balance between sessions in which service users and carers input together (or it does not matter particularly whether input is from a service user or a carer), and the creation of particular slots within the curriculum to look at carers' or service users' experience separately.
- Where perspectives may differ, students need to be enabled to integrate both within their work – perhaps through case studies or problem based learning approaches.
- Service users and carers may not wish to be involved in the same way. Ask them how they want to deal with this.

3 Spectrum of Involvement

Service users and carers have the potential to make a major contribution, not just to direct delivery, but to all aspects of the educational process, and we suggest that this should be an explicit goal of programmes.

In this section, we will look at each aspect of involvement in turn, suggesting some pointers to achieving good practice, starting with direct involvement in teaching. We will then move on to consider involvement in course planning, programme management, student recruitment and selection, practice learning, assessment and evaluation. Finally we will turn our attention to the role to be played by users and carers on the other side of training 'fence', as course participants.

Each section is illustrated, where possible, by examples of where service user and carer involvement has been, or is in the process of being, implemented. These are offered as examples of current practice, in the spirit of this Guide that there is much to be learned from experience. In following up these examples, please bear in mind that programmes and people change and practice may alter with time.

We have attempted to keep examples brief. Each is accompanied by details of a contact person from whom more information can be obtained. In addition, further information about these and other examples, and updated contact details, will be made available on the mhhe website. If you have other examples to share, please get in touch, via the mhhe website feedback form **www.mhhe.ltsn.ac.uk.** or by post (see address on inside front cover).

3.1 Direct delivery of learning and teaching

Although this is the most common area for involvement, it can still feel daunting to potential presenters. It can also feel immensely rewarding if it goes well – a chance to be heard and an opportunity really to influence the attitudes and professional practice of students. Many people have started by standing up at the front of a teaching session and telling their stories. However, it must be recognised that this can be stressful, in that the material within the stories can be very personal and painful. People will need to feel supported.

A crucial factor in determining how receptive students may be to service user and carer viewpoints is the degree to which the rest of the teaching team reinforces a value base of mutual respect between teaching staff, students, service users and carers. This must allow for challenge to traditional modes of practice and take direct experience seriously as a source of knowledge and understanding.

It is disrespectful to service users and carers if they are left having to carry their messages on their own, and it is unlikely that effective learning will take place. It is similarly disrespectful to students if service users or carers take out their anger about poor services on a captive audience of students. This is unlikely to foster among students the confidence or the capability to work in partnership in the future. The Highland User Group has given some thought to this. Their comments relate to the training of professionals but are equally applicable to pre-registration education:

"We initially made the assumption that professionals can deal with the impact and emotional content of our testimonies, and there was no need to ensure their safety and ability to deal with what we had to say. Clearly this is not necessarily the case, and over time we realised that some people found it extremely difficult to respond or react to what we had said. In some instances this led to complete silence in training following HUG members' testimonies. We tend to live with so much pain and distress, and learnt to speak about it very openly and honestly – not appreciating that what was normal for us, could be very distressing and perhaps shocking for other people (this was particularly so in the case of self-harm training). Consequently, we made a number of changes to our training, including establishing ground rules to cover all participants, a clearer focus on the learning aims of the participants and taking time to 'set up' training, for instance, explanation about its aims, what we can and cannot achieve/deliver, ensuring safety to ask questions etc."

Further information about the Highland Users Group is available at **http://www.hug.uk.net/** or contact Emma Thomas at **hug@hccf.org.uk**

Increasingly, contributors are finding that telling their stories within a user or carer 'slot' may be only one of a number of ways of contributing to teaching and learning.

For example, they may:

- invite students to reflect on their own experience so that they can begin to empathise with what it is like to be a service user or carer. During discussion, the presenter can link students' feedback to relevant material from their own experience or from that of other people that they know.
- be involved in devising problem or enquiry based learning materials to enable students to get to grips with issues for themselves - and then act as consultants or resource people to the groups as they work through the task.
- work alongside students as they learn listening, communication, counselling and other skills. This could involve setting exercises, playing roles and offering feedback.

Not all direct delivery has to be face-to-face. *Service users and carers may:*

- work with students in web based discussion groups or act as e-based consultants for problem or enquiry based learning.
- be commissioned to make a video or a written piece about a particular issue or experience. Art produced by people with lived experience of mental ill-health is increasingly accessible for use in teaching. Service users and carers could devise questions for discussion following the video or other input and be involved in facilitating this discussion via an e-learning or distance learning package.

Pointers towards good practice

- Service users and carers may welcome opportunities to develop their confidence and expertise as educators, perhaps by taking part in 'training the trainers' workshops or programmes. This may include work on presentation and assertiveness skills, and also input around interactive and student centred educational strategies (see Section 4.7).
- Users and carers with experience in training have a crucial role to play in helping others, who may be newer to this area of work, to understand their rights and responsibilities and to devise strategies for coping with boundaries (e.g. responding to questions which may be inappropriate).
- There may be a need for teaching staff to have opportunities for training and reflection to enable them to respond positively to the challenges to traditional approaches that embracing user and carer involvement can bring (see Section 4.4). Students will also require some preparation.
- Making plenty of time for service users, carers and teaching staff to get to know one another will pay dividends in terms of effective delivery of teaching.
- Jointly led teaching with other teaching staff may be effective in integrating user and carer perspectives within the overall course content, while also demonstrating partnership in practice. However, if they are to work, these sessions need to be a genuine collaboration of equals.
- Service users and / or carers may wish to devise and deliver their own sessions or modules.
- Most people prefer the support of a co-presenter – either another service user or carer, or a member of teaching staff that they know well.

Remember

- Discuss fully with people what they want to contribute and how they want to do it.
- Ensure that minority viewpoints and experiences are reflected in the teaching – for example those of service users from Black and minority ethnic groups or lesbian and gay people.
- Check what support and training people want before their contribution.
- Consider how people can get feedback on their contribution.
- Treat service users and carers as equal contributors. Ensure that payment rates are the same as for other visiting lecturers (see Section 4.9).

Direct involvement across the disciplines

In Barnet, a local service user group (Barnet User Voice) has been involved in recurrent cycles of workshops to teach interview skills to doctors training in psychiatry at the senior house officer (SHO) level. Trainees report that they are using their experience in everyday clinical practice; and colleagues from other disciplines that they have noticed an improvement in trainees understanding of the psychological world of patients. Recently, a confidential group has been established in which trainees can discuss their own feelings and responses without users present. For more information contact George Ikkos **George.Ikkos@barnet-pct.nhs.uk**

At Middlesex University, the Richmond Fellowship Diploma in Community Mental Health includes a module on "the service user experience", designed and delivered by service users. Further information about this course is available on the mhhe website **www.mhhe.ltsn.ac.uk** or from: Peter Allen **peterallan@richmonfellowship.org.uk**

Trainers from Leeds Voluntary Sector Mental Health Forum and 'Experts by Experience' have devised and run training session in 'anti-discrimination and mental health' for undergraduate medical students at Leeds Medical School. These look at the way stigma is all around us, how it feeds prejudice and leads to discrimination. Efforts are made to encourage students to engage with the training on a personal, emotional level, not just intellectually. So they are challenged to look at their own experience of distress and mental health, their own prejudices and what positive measures they can take when they become doctors. Contact: Barry Ewart **b.r.ewart@leeds.ac.uk** or Phil Green c/o **info@volition.org.uk**

A carer and service user are both involved in training for approved social workers provided by the South West Training Consortium. The carer input consists of an awareness-raising session during the first taught part of the programme, during which issues of confidentiality and difference of opinion are explored. A follow up session, during the second block of teaching, has an explicit focus on "the nearest relative" and draws on trainees' experience on placement. The service user and carer liaise but deliver their input separately, and deliberately not "back-to-back". User and carer input has increased over time at the request of the trainees, and now encompasses assessment, based on an extended interview with a service user and non-related carer. An opportunity to shadow a more experienced trainer at the outset is provided and users and carers are actively encouraged to sit in on, or participate in, any session of the programme that they choose. For further information contact Stella Harris **frankstellaharris@hotmail.com**

A very helpful range of examples of user involvement in social work training (not specifically mental health related) can be found in the Social Care Institute for Excellence knowledge review on "Involving service users and carers in social work education" (Levin, 2004) and the report "Learning and Living together" (GSCC/SCIE, 2004) – both available at **www.scie.org.uk**

Involvement in training - something different

Scenarios

- In the medical school at the University of Leeds, a series of workshops was held to consider how service users could most effectively be involved in facilitating student learning of communication skills. Through a project, funded by the Higher Education Academy Subject Centre for Medicine, Dentistry and Veterinary Science, people with lived experience of mental distress have been involved in devising "simulated patient roles". They have also been involved in helping students to develop their awareness of their own vulnerabilities and needs, and skills in looking after themselves; breaking down some of the stereotypes about how doctors and patients differ. They will be helping to deliver these inputs into student learning and assessment during the next academic year. Contact: Penny Morris **p.a.morris@leeds.ac.uk**
- A one-day accredited training event for GPs brought together users and carers to present their experience. Adopting a more collaborative approach the following year, the organisers devised scenarios for the GPs, users and carers to explore together. For further information, contact David Shiers, **david.shiers@doctors.org.uk**
- At Sheffield Hallam University a group of mental health service users and carers has been developing case studies for interprofessional action learning sets (both face to face and on-line) Contact: Helen Armitage **h.r.armitage@shu.ac.uk**

Art and Creative Writing

- Premila Trivedi designed and runs a creative writing course for occupational therapy staff (4 half day sessions over a four month period); describing this as “the most exciting bit of training I have ever done, allowing me and other users to use our own coping mechanisms (ie creative writing) to educate Occupational Therapists”: Contact: **premila.trivedi@slam.nhs.uk**
- Aidan Shingler has provided training for professionals using slides of his “Beyond Reason” exhibition – an exploration of schizophrenia in pictures and words. Aidan can be contacted via his website: **http://www.beyondreason.org.uk/**

Drama

- A short, humorous play about a group of patients in a psychiatric unit was written and performed by a survivor group. An Open University tutor, who saw the play and recognised its potential as a teaching resource, helped to obtain funding for production of a video for use in a new Open University Mental Health course, Challenging Ideas in Mental health. For further details contact: Terry Simpson. **TezBeulah@aol.com**
- The TELL (Training, Education, Listening and Learning) Group in Lisburn, Northern Ireland is made up of service users and professionals, working together to achieve change. Members use their experiences, expertise and knowledge to provide training in mental health awareness while also endeavouring to begin to tackle stigma. Group members devise role plays through talking about their own experience, what they have found difficult, what has worked well and what might be done differently in the future. These are then used in training sessions with students, mental health professionals and others. Recently the group worked alongside a playwright and an actress/director to develop skills which will further enhance their ability to use creative approaches in their training. Contact: **Pauline_Graham@DLTrust.n-i.nhs.uk**

A panel of experts by experience

- The CAPITAL project has been involved in training multidisciplinary teams of workers in West Sussex, using the Psychosis Revisited materials (Bassett et al, 2003). An "interview panel" was set up in which the director of CAPITAL interviewed two other service users. Students submitted additional questions on post-it-notes which were vetted and grouped during a break in the session. For further information, contact Mark Hayward **m.hayward@surrey.ac.uk** or see the case study at **www.mhhe.ltsn.ac.uk**

An e-learning module

- Under the UK Healthcare Education Partnership, a team from City University collaborated to produce an e-learning module on user and carer involvement. Details can be found on the UK HEP website: **www.ukhep.co.uk**. The authors of the module have now been commissioned to produce a similar module on user and carer involvement in primary care for the Graduate Primary Care Mental Health Worker programme. Contact: Ian Light **i.light@city.ac.uk** or Julie Attenborough **j.a.attenborough@city.ac.uk**

3.2 Course / module planning

From the 'early days', when service users and carers were only involved in planning their own sessions, we have now moved to a situation where it is more common for service users and carers to participate as members of the teaching team that will design and deliver an entire module or programme.

Where courses are already running, it may not be feasible to 'go back to the drawing board' and make radical changes. However, there may be possibilities for incremental developments, and service users and carers can be fully involved in taking these forward. Furthermore, when programmes come up for revalidation, or where there are major changes in external requirements, this can be used as an opportunity for more far reaching consultation with service users and carers as key stakeholders.

One issue that needs to be clarified from the outset is what value is going to be attached to user and carer perspectives. Are they going to be seen as:

A. additional viewpoints that merit some limited consideration alongside the established 'professional' approaches that form the core of the programme

B. equally valid perspectives to be introduced as part of a critical dialogue between different (and potentially competing) viewpoints, or

C. setting the core agenda and value base for the whole module / programme, so that they influence how all inputs are presented?

While A may be seen as a useful starting point, we would suggest that only B or C form the basis of good practice.

It can also be helpful if service user and carer involvement is part of a spectrum of external input, which also draws on the experience, and perspective of practitioners.

Pointers towards good practice

- Where is the planning done? Is it in an environment which feels comfortable to service users and carers? Practicalities like offering people lunch, having regular breaks and not making meetings too long can make a big difference.
- Who is involved? Do service users or carers feel like a small minority within the planning team or is representation more equal? Being the only service user / carer can feel intimidating unless there have been opportunities to get to know other members of the teaching team very well. This may be compounded if the service user or carer is also the only Black person or young person in the room. Do service users and carers have back-up and support from a wider reference group or user / carer run organisation?
- What do service users and carers feel it is important to cover within the overall breadth of the course? Every aspect of teaching and learning should incorporate the experience of users and carers even if they are not directly involved in a particular session or event. Service users and carers have begun to be consulted about the content of national training programmes, and this needs to be reflected at the local level.
- Do service users and carers have full access to library, IT, photocopying, administrative support and other resources that are available to other members of the planning team?
- Service users and carers should be involved in developing reading lists that look beyond traditional material and include the growing literature that has been produced by, or in conjunction with, service users and carers.

Remember: Always consult with service users and carers from as early a stage as possible, and make them equal partners

Content of training - Service user views

- What did service users feel should be included in the training of the new Primary Care Graduate Mental Health Workers? For further information about a recent consultation contact Colin Gell at **ColGl@aol.com** or see the mhhe website **www.mhhe.ltsn.ac.uk**
- At the University of Nottingham a service user group, Making Waves, was commissioned by the School of Nursing to make recommendations about the pre-registration mental health nursing curriculum. The group met five times and produced a report which included recommendations about the content of teaching. Funding has now been obtained from the university teaching and learning development fund to take this initiative forward in the form of the PINE project (Participation in Nursing Education). For more information, contact: **theo.stickley@nottingham.ac.uk** or Torsten Shaw **torsten@makingwavesonline.org.uk**
- Service user and carer representatives, including people with experience of mental health services, were consulted at the planning stage of the new social work degree and their recommendations were a key influence in the development of the requirements for social work training (Levin, 2004)

Involvement in course planning

- A reference group advises on user and carer input into the North East Approved Social Work Programme. It meets three to four times a year at the base of one of the service user groups. Attempts have been made to involve all parties at each stage (e.g. reporting back to programme management board on developments/suggestions made) so that "there is a shared sense of ownership in moving forward". For further details, contact Jeanie Molyneux, **jeanie.molyneux@unn.ac.uk**
- At the University of the West of England, carers have been involved in development of the new MSc in mental health and BSc in acute in-patient care as well as in contributing to the pre-registration nursing programme. Contact: Chris Chapman **c.chapman@bath.ac.uk**
- In the School of Nursing at the University of Southampton, a user reference group was established to contribute to the design, delivery and evaluation of pre- and post-qualifying mental health programmes. This included representation from many user and carer organisations. For further information, contact Steve Tee at **s.r.tee@soton.ac.uk**

3.3 Programme management

To ensure that a programme is user and carer focused it can be very helpful for service users and carers to be involved in its management. This may suggest the need to review current practice. The meetings of many conventional management groups can, to an outsider, seem lengthy, boring and impenetrable. Moves to make processes more transparent and easy to understand may actually be of benefit to all involved.

As an example, it may be useful to establish periodic strategy and decision-making meetings, separate from the day-to-day running of a course, and to prioritise service user and carer involvement in those. It may be helpful to look at decision making processes to ensure that, however unintentionally, they do not reproduce bad experiences service users and carers may have had elsewhere in the mental health system e.g. of being marginalised, patronised or ignored.

As a general rule, there should always be more than one service user and carer involved and it would be preferable if a group of people could be involved (perhaps on a rota basis), thereby bringing a wide range of experiences to the running of the programme and not putting too great a burden of responsibility on to one person. Involvement in programme management often evolves from engagement in direct teaching:

Involving children and young people

At Anglia Polytechnic University, young people have been involved in delivery of teaching on a new BSc (Hons) and MSc programme on child and adolescent mental health. An initial approach was made to a local advocacy group run by MIND where service users were already involved in supporting other children and young people with mental health problems. The nature of the advocacy service, and its orientation to the needs of young people, meant that the initial meeting had to be scheduled out of working hours at a weekend. A key factor in the success of this project was ensuring that the young people had a sense that this was "their show" and an opportunity to influence practice. It is intended that involvement in direct delivery will now lead on to contribution to the programme management committee.

Contact: Steven Walker **s.walker@apu.ac.uk**

Pointers towards good practice

- Involve service users and carers in discussing course management structures and how meetings will operate. How will decisions be taken, for example? If there is disagreement, how can it be ensured that service users and carers will not always feel outvoted or over-ruled?
- Discuss with service users and carers how they wish to contribute to meetings. Would they welcome a user and carer "spot" on the agenda, and/or a chance to contribute to all areas of the discussion? Pre-meetings for service users and carers can be a real help in enabling people to 'get up to speed' and consult with each other on any issues or concerns and how these will be raised in the meeting itself
- Other management group members may need some training in involving service users and carers. Local service user, advocacy and carer groups can be a valuable source of advice, training and information about current issues for service users and carers.
- Consider where and when a meeting is to be held. Have people been given sufficient notice? Is 9 o'clock Monday morning or 4 o'clock Friday afternoon really the best time? Does a meeting really need to last three hours without a 'comfort break'? Will the room feel comfortable to service users and carers?
- Papers for meetings - are they too difficult to read and too long? Are there other ways that information can be given?
- Put in place agreed arrangements for follow up support for people to debrief where meetings may have been heated or difficult.
- Would it be possible to employ a service user or carer as a joint module / programme co-ordinator?

Remember

- *Always ask service users and carers how they want to be involved.*
- *Practicalities like offering people lunch, ensuring accessibility of the venue, having regular breaks and not making meetings too long can make a big difference.*

Involving service users in programme management.

- The recently launched COMENSUS project at the University of Central Lancashire will involve a range of service users in all aspects of learning and teaching including programme management. For more information contact Mick Mckeown **mmckeown@uclan.ac.uk** or Eileen Johnson **emjohnson@uclan.ac.uk**
- At Oxford Brookes University, a group of service users will be established to advise on all aspects of training across all areas of health and social care For more information contact Bill Spence **w.spence@brookes.ac.uk**
- At City University service users and carers are involved in teaching and as members of the programme management teams in mental health nursing and inter-professional practice in health and social care. For more information contact Patrick Callaghan **patrick@city.ac.uk**

3.4 Recruitment and selection of students

There is a growing acknowledgement in interview criteria, across all disciplines, of the importance of both academic ability and 'people skills'. Yet service users continue to express concern about the values and attitudes of some of the staff they encounter in practice. The active involvement of service users and carers in interviews, alongside academics and practitioners, can significantly enhance an assessment of how a potential recruit relates to other people.

An additional benefit of involving service users and carers in recruitment and selection is that, right from the start, potential students can see how the experience of service users and carers is valued. This can serve as an effective way of advertising the value base of the programme, and of moulding the attitudes and expectations of students. Where places on courses are offered without interview, as is the case in some programmes, the involvement of service users and carers at open days is of particular importance.

Pointers towards good practice

- Wherever possible, service users and carers should be involved in the whole process of recruitment and selection from how the course is publicised, through to the short-listing and interviewing of students.
- In order for participation to be coherent rather than tokenistic, service users and carers need to be partners in drawing up clear selection criteria in advance and contributing to shortlisting meetings. There may be a need for open debate and wider consultation at this stage.
- Be creative in exploring with people how they might be involved both in 'paper' selection processes and in individual or group interviews – e.g. they may wish to be involved in drawing up agreed interview questions, but not in acting as interviewers, although they might wish to participate as observers.
- Joint briefing and training sessions should be provided for service users, carers and teaching staff to help them to work together effectively. These should include input on equal opportunities and clear policies on confidentiality.
- If the involvement of users and carers in selection processes is to be meaningful, they should be equal members and their opinions given equal value. If there are differences of view, there must be a clear understanding of how these will be resolved in a way that gives equal weight to all members of the selection team. One possible approach is to give each participant an individual right of veto, as long as this is linked to the previously agreed selection criteria.

Remember:
It is important to ensure that the group of people involved is inclusive of the diversity of potential candidates, with regard to race, gender etc.

Examples of involving people in recruitment & selection

- In the social work department at the University of Birmingham, a panel of service users and carers is involved in the selection of all students.
  For more information contact **r.j.littlechild@birmingham.ac.uk**
- In the West Midlands service users and carers are on the steering group and will be involved in the selection of trainees for the new doctoral training programme in Clinical Psychology.
  For more information contact Helen Dent at **Helen.R.Dent@nsch-tr.wmids.nhs.uk**

3.5 Practice learning

Practice learning provides the ideal opportunity for students to explore how to build constructive partnerships with service users and carers, and to learn about mental distress, and problems of daily living, from those with immediate and direct experience. How well this works out in practice can depend on the ethos of the placement setting – are practice supervisors and other team members modelling a genuine commitment to working with people, rather than performing interventions upon them?

Over and above maximising the opportunity for students to learn from, and with, those for whom they are providing a service, it is important to explore how other service users and carers may also input into their practice learning – perhaps as consultants or mentors.

This may involve a joint approach between Higher Education Institutions and the Trusts and other agencies where students undertake their practice. In some instances this may be made easier where service users and carers are already actively involved in service delivery – for example as consultants within assertive outreach teams, or in running support groups. In other instances, a course may take responsibility for training up service users and carers in supervision skills so that they can work alongside practice supervisors in supporting the students' learning.

Pointers towards good practice

- Are service users and carers involved in the training and continuous professional development of practice supervisors? Are there other mechanisms for ensuring that they are 'on message' in relation to partnership working?
- As well as having to demonstrate any specified practice competences, students should always have explicit learning objectives focused on developing their ability to work in partnership with service users and carers – demonstrating attitudes, values and people skills in line with the Ten Essential Shared Capabilities (Hope, 2004).
- Is there any possibility of students having some of their practice learning experiences in a service user or carer run organisation, or in a setting (such as a voluntary organisation) in which service users and/or carers play a significant role in setting the direction of the service?
- Where students are placed in more conventional settings, could they have some supervision or consultancy from service users and carers – perhaps in the form of a group supervision session in which they present and discuss their work. There would need to be strict safeguards to ensure confidentiality – by anonymising material and / or by involving service users and carers from a different locality.

Remember:
Individuals and carers who are receiving services have an absolute right to a service that is tailored to meet their needs and not the learning needs of a student.

Involving people in practice learning - where is it happening?

We did not find it easy to find examples of the approaches outlined above, but there are clear examples of work which has potential for development.

Client attachment

The idea of "client attachment" (Turner et al, 2004) allows student nurses to gain practice experience through forming therapeutic attachments with individual users of services, rather than through a series of location based placements. The above paper describes a pilot project that evaluated client attachment with preregistration student mental health nurses. Using semi-structured interviews, the researchers identified the students', their supervisor's, and the service users' experiences. Most participants agreed that students were able to learn relevant and appropriate skills, and to consolidate experience - increasing motivation, autonomy, organisational skills, and confidence. Whilst not having a specific focus on the role of service users and carers as educators, this approach has clear potential for the closer involvement of users of services and carers in supporting students' learning.

3.6 Student assessment

A useful first step is for service users and carers involved in the programme to contribute feedback on students' academic or skills-based work. Alongside this, those who receive direct services from a student on placement may be invited to contribute structured feedback on particular areas of the student's capability, attitudes or skills. Other teaching staff can then take this feedback into account in giving a final mark. If this approach is used, there is a need to ensure that people's views are taken seriously and that this is not a token exercise.

Arrangements for obtaining feedback in placement settings need to ensure that students do not feel that they have to appease service users and carers in order to receive a positive assessment, and service users and carers feel safe to give honest feedback in the knowledge that it will not affect the service they receive. One model would be for the practice assessor to ask specific questions that focus on values and skills (and not whether they were 'nice'). These questions could be devised in conjunction with service user and carer consultants, to ensure that they are relevant and understandable.

This could be the first step in a process in which some service users and carers, with appropriate training, may become markers in their own right – perhaps marking jointly in the first instance. Within some disciplines there is a long history of non-academics (usually practitioners / clinicians) marking students' work – and this has worked well where marking guidelines are clear. Similar principles could be applied in relation to bringing on service users and carers as markers. With a suitable level of experience, service users and carers might ultimately be able to contribute a valuable perspective as external examiners.

Such progress may entail overcoming certain barriers – in terms of reviewing formal academic regulations and procedures, and in terms of exploring attitudes on the part both of teaching staff and of service users and carers themselves.

Pointers towards good practice

- Students should be made aware how users and carers will be involved in their assessment and the rationale for this.
- Organise preparation and training sessions for service users and carers, including joint sessions with other teaching staff (eg moderation exercises where they are going to be formal markers). Value the particular skills or perspectives that they bring.
- Service users and carers should be involved in devising assessment strategies and setting criteria as well as providing feedback or undertaking marking
- Role-plays, practice portfolios, accounts of problem or enquiry based learning, or assignments which relate to students' developing value base and professional development may lend themselves particularly well to feedback or assessment by service users and carers.
- At least initially, service users and carers may take longer to undertake marking – and this will need to be allowed for.
- Offer support – particularly when people may feel the need to give negative feedback. Can they easily seek advice and / or a second opinion? Rather than working in isolation, can timeslots be arranged in which service users and carers can undertake marking together, perhaps alongside teaching staff?
- Universities and professional bodies may need to revise criteria for the appointment of external examiners in order to open the way for service users and carers with experience of assessment to be appointed.

Remember:
Always consult service users and carers about how they want to be involved.

Users and carers as Assessors

Jewish Care obtained funding from CCETSW in April 2001 for a project to examine the costs and benefits of service user involvement in the assessment of candidates for the Certificate in Community Mental Health. User assessors were involved in designing assignments, reading them and (in three way meetings with the student and accredited assessor) providing feedback. Both assessors and candidates found service user feedback helpful and it contributed to learning on all sides. The project was steered by a consultant, Fran McDonnell, and had a very thorough approach to selection, training, support and payment of service users. A wider reference group of service users decided on the selection criteria and appointment process for user assessors. The initiative is now in its third year. For further details, contact Erica Jeeves **ejeeves@jacare.org** or **fran.mcdonnell@btinternet.com**.
A full report on this project is available on the good practice guide section of the mhhe website **www.mhhe.ltsn.ac.uk**

At the University of Birmingham users have been involved in providing feedback on students' portfolios of evidence submitted for a module on User Participation and Recovery on a master's degree in community mental health. Training is provided for the user markers, along with opportunities for them to come together with students to explore the learning outcomes for the module and how they might be evidenced. For further information contact Diane Bailey **D.E.Bailey@bham.ac.uk**

A model for involving service users in classroom work was set up and subsequently evaluated in 1998 (Wood and Wilson Barnett). The method involved collaborative classroom activities with students, user representatives and lecturers to explore the dynamics of an assessment recently undertaken by a student in practice. Contact Janet Wood **janet.wood@kcl.ac.uk**

The MIND Day Centre in Hereford has been used as a placement for student nurses from University College Worcester since 1996. Service Users are involved in providing feedback on the student's placement as it proceeds. Service users are asked: how they got on with the students; whether they felt listened to and how this was demonstrated; whether they felt that their experience was understood; whether the student followed through on what they had said that they would do; whether they ever made the service user feel uncomfortable. Feedback from the overall membership is collated by "member representatives", cross-referenced with the Assessment of Practice criteria statements and contributes to the overall assessment at the end of the student's placement.
For further details, contact: Phill Lister **LISP1@worc.ac.uk** or Julia Mathevosian **heffernan@herefordshire-mind.org.uk**

At City University a project has been set up to consider how users and carers can most effectively contribute to assessment. Ian Light would be interested in hearing from others with an interest in developing good practice in this area: **i.light@city.ac.uk**

3.7 Course Evaluation

In many instances, evaluation consists of students completing satisfaction questionnaires and / or taking part in group discussions at the end of a module or course. It would be straightforward for service users and carers who have contributed to the module / course to take part in such an evaluation process.

Contributors could be invited to complete questionnaires about how they experienced their involvement (see Section 5.1) and to take part in discussions with students and teaching staff. Alongside this, students could be asked to comment specifically on how they saw the integration of service user and carer perspectives within the course / module, and on the 'added value' to them (if any) of having service users and carers involved in their learning (see Section 5.2).

There may be a desire to go beyond this and evaluate outcomes – what difference has service user or carer involvement made in terms of students' subsequent practice? Has it equipped students with values and capabilities that are relevant for practice within a modern mental health service? And has it delivered outcomes in terms of the values, attitudes and 'people skills' that are most valued by service users and carers (see Barnes et al, 2000)?

To take this forward, commissioners and providers of mental health education would need to work with service users and carers and other stakeholders in determining the criteria to be used to evaluate programme outcomes (Forrest & Masters, 2004). Once these are agreed, service users and carers could play a vital role in evaluating the extent to which these outcomes are achieved. There is now considerable research expertise around service user and carer evaluation of services (Rose, 2001). This could potentially be applied to evaluating how courses impact on students' capabilities in practice.

Pointers towards good practice

- It can be valuable for service users and carers who contribute to the programme to give regular feedback on process issues as the course is progressing
- If outcomes in terms of students' practice are to be evaluated, service users and carers may need training in research / evaluation methods to enable them to be involved. Growing numbers of service users and carers are involved in monitoring and evaluating mental health services, and may prove a valuable resource.
- If service users and carers are suggesting improvements or changes, how will programmes deal with this?
- How is any external evaluation going to be resourced? Who will have access to and be expected to read reports – for example, commissioners, professional bodies involved in accrediting courses and, in higher education, the Quality Assurance Authority (QAA)?

Service user involvement in course evaluation

- Service users are involved in evaluation of courses on the Nursing Programme at the University of Southampton For more information contact Steve Tee at **s.r.tee@soton.ac.uk**
- At City University carers and service users are asked to participate in regular sessions to evaluate modules/programmes for nursing and inter-professional practice in health and social care. For more information contact Patrick Callaghan at **patrick@city.ac.uk**
- A research project at Imperial College aimed to compare the impact of teaching delivered by professionals with that delivered by service users on undergraduate medical student attitudes to mental ill-health. What began as research has now been incorporated into the curriculum. Contact: Mike Crawford **m.crawford@imperial.ac.uk**
- The SUITE training the trainers initiative includes training for service users in monitoring and evaluation of training. Contact Steph McKinley **stephanie.mckinley@slam.ac.uk**

3.8 Service users and carers joining courses as participants

In the preceding sections, we have talked about service users and carers contributing to the provision of teaching and learning in a variety of different ways. It is equally important to encourage service users and carers to take part in the learning, as students or course participants.

Whereas, in the past, students with a background of direct experience of mental distress often faced discrimination when seeking to enrol for mental health courses or professional training routes, such experience is now starting to be seen as a positive asset by many programmes – both in terms of the student's ability to comprehend mental health issues, and in terms of their potential capability as a practitioner.

As a response to the Special Educational Needs Disability Act 2001, there is a growing awareness within higher education of the needs of students with mental health problems and a range of support structures are developing in response to this. There is now a legal obligation to ensure access and make 'reasonable' adjustments for such students – and failure to do so could result in legal challenge. Such adjustments may include having a friend or carer to accompany them in teaching sessions during periods when they may feel a little unwell or under-confident, making adjustments to assessment strategies so as to minimise stress and anxiety, or ensuring that they can access student counselling services should they need to. However, a potential area of discrimination that can remain relates to the criteria used within occupational health checks, where these are required for particular forms of professional training.

In addition to enabling service users and carers to participate as students working towards a recognised qualification, it may be possible to invite them to join in the learning process of particular modules or sessions. Their participation in exercises and discussions may be valuable as a first step to build up confidence and understanding before enrolling on a more extended course of study. Just as important may be the benefits to other students in learning from their knowledge and perspectives and experiencing how to 'do' partnership at first hand within the learning peer group. This approach has a unique potential to break down barriers between 'us' and 'them' – or to prevent such divisions occurring in the first place.

Support to students with experience of mental distress

- Students in Mind is a new project which will recruit, train and support student volunteers to support other students who are experiencing mental distress. The service will act as a stepping stone to other services:
  www.studentsinmind.org.uk
- On the social work programme at the University of Bristol, thought has been given to development of a support group for students experiencing mental health problems, run by an external facilitator. Joan Langan would be interested in hearing from others considering similar developments. Contact: Joan Langan
  j.langan@bristol.ac.uk
- The website of the Oxford Student Mental Health Network has links to a number of useful resources
  http://www.brookes.ac.uk/students/services/osmhn/
  as does the briefing paper recently produced by the National Disability Team (Wray, 2004) available from
  http://www.natdisteam.ac.uk

Pointers towards good practice

- Literature and other information about courses should positively encourage applications from service users and carers
- Regular contact should be made with user/carer networks and service providers to make it clear that participation by service users and carers is welcomed.
- If someone with a declared mental health difficulty is showing interest in a particular course, ensure that they are given as much encouragement as possible, and that they are informed about what specific forms of assistance or adjustment they may expect.
- Effective support may involve close liaison and joint working between support services in Higher Education Institutions and services or support systems outside.
- People may need periods of 'time out'? How can any time lost be made up?
- Be imaginative in considering how particular sessions or modules of a programme may be opened out to service users and carers as participants, without their having to enrol for a qualification. They should be provided with a Certificate of Attendance – which may prove helpful if they later wish to apply to join a more extended course of study.
- If service user or carer participants are not going to receive a recognised qualification or award, or some other tangible benefit, they should receive payment for their time. Funding for this may be sought, from sponsoring Trusts or local authorities. Alternatively, funding may be available by linking in to wider social inclusion initiatives that encourage wider participation in education or seek to enable people with disabilities to gain access to employment.
- All teaching staff, including user and carer trainers and external practitioner contributors, need to be made aware that there may be students / participants who have direct experience of mental distress – and they need to make sure that this is respected and valued.

Remember:
Ensure that service user and carer participants are treated as equals: no discrimination!

Joining courses/modules as participants

Moving On

- Moving On is an informal group of people who have used or worked in mental health services who undertook 'training the trainers' programme together funded through Northern Birmingham Mental Health Trust. Having experienced the liberation of breaking down barriers within the group, Moving On successfully negotiated with Birmingham Social Services that local service users were offered places on in-house Introduction to Mental Health and ASW Continuing Professional Development courses, and would be paid for their time as this would not lead to any recognised qualification for them. An ASW participant described this as her first experience of 'genuine partnership training'. It allowed the exploration of complex practice issues within a learning group where everyone was, first and foremost, a human being, and was not defined by their label as user or professional. For more information, contact Stewart Hendry **stewarthendry2003@yahoo.co.uk**
- A number of programmes, such as the RECOVER programme, and the Open University modules "Mental Health and Distress" and "Challenging ideas in mental health," actively encourage the involvement of service users as participants and have given thought to how to recruit and support them. For more information contact Di Bailey (Recover programme) **d.e.bailey@bham.ac.uk** or Jeanette Henderson (Open University) **jeanette.henderson@open.ac.uk**
- At the School of Nursing at the University of Southampton a "cooperative enquiry "between nursing and social work students has been established. For further information contact Steve Tee **S.R.Tee@soton.ac.uk** or read the case study written by Steve and Tina Coldham on the mhhe website **www.mhhe.ltsn.ac.uk**

4 Initiating and Sustaining Involvement

In this section, we explore some practical steps towards achieving sustainable service user and carer involvement – including how to overcome some of the common barriers faced by individuals and by organisations. We also look at some of the infrastructure and practicalities that may need to be sorted out if involvement is to be effective.

4.1 Getting started (or getting moving again): what are the barriers and how can we overcome them?

Teaching staff

Some of the most common barriers may be:

1. isolation
2. lack of information
3. inertia – it can feel a lot easier to carry on with familiar ways of doing things
4. the existing culture of the course and / or the institution may feel hard to challenge or change
5. lack of time to reflect, discuss and plan
6. lack of resources

How to overcome these:

1. Being a lone voice trying to bring about change can feel a very daunting position to be in. It can be vital to seek allies – identifying those colleagues who may seem more favourably disposed towards embracing service user and carer involvement and/or seeking out colleagues in different disciplines, or those working in other institutions. Bringing up these issues, formally or informally, within professional network meetings may be a useful source of support.
2. We hope that this Guide will provide some useful information. Beyond this, a number of useful articles, reports and guidance notes are listed in Section 7.
3. A sense of inertia may be driven by fears and anxieties – what might one have to lose in terms of respect and status, and will one find one has the skills and approach necessary to work alongside service users and carers? It may also be driven by ongoing pressure of work, burn-out and stress. These may be serious issues for teaching staff irrespective of whether they are working alongside service users and carers – it is just that any potential innovation is likely to bring these issues to a head.
4. There may well be aspects of the existing culture of the course or institution which seem resistant to change. This is discussed more fully in Section 4.4. In general, it may make sense to start small – negotiating limited opportunities to pilot new ways of working, and trying to identify potential 'easy wins' where benefits may be relatively straightforward to establish. Thorough evaluation of these limited successes may then be used to make the case for more far reaching change.
5. Within the context of competing demands on time, it may be hard to carve out sufficient time to think about developing service user and carer involvement. However, as this expectation is increasingly placed on courses, managers may be willing to support some reallocation of duties in order to allow committed individuals to take this forward.
6. There are likely to be resource implications. However, small sums of money can go a long way in inviting the first service users and carers to come on board and begin to make a meaningful contribution.

Service users and carers

Some of the most common barriers may be:

1. isolation
2. lack of confidence and self-belief
3. feeling 'blitzed' by jargon
4. lack of understanding of learning and teaching strategies

How to overcome these:

1. It can be crucial to have the support of others – e.g. joining (or forming) a user or carer group or network. Mental health Trusts, local authorities, MIND, Rethink or other voluntary organisations, or NIMHE Regional Development Centres may have details of support or training groups that already exist locally.
2. While contributing to education and training may not suit everyone, a surprising number of service users and carers, from all sorts of backgrounds, have found that they have something valuable to offer. Most of these, at the outset, would not have believed that they would subsequently be able to do what they have done. An opportunity to talk to an 'old hand', perhaps through a support group or a training session, can be an inspiring experience. Specific training around assertiveness and presentation skills, and around different approaches to teaching and learning, can also be particularly helpful (see Section 4.7).
3. Unfortunately, in any field, people can tend to develop their own specialist language or shorthand – and this can feel very excluding to an 'outsider' coming in. Educators need to recognise this, start to use less jargon and explain what they mean better. They must also encourage service users and carers to ask (and keep asking) what particular terms or abbreviations mean until they are understood by everyone.
4. User and carer involvement means that everyone involved will have to find new ways of delivering learning. No-one has all the answers and everyone is on a steep learning curve together. Experience of receiving services or supporting others can be valuable in coming up with imaginative and creative ways of facilitating students' learning.

Course managers

Some of the most common barriers may be:

1. competing pressures and priorities
2. uncertainty in leadership due to lack of personal experience of service user and carer involvement in education

How to overcome these:

1. Key into the 'top-down' levers for change in terms of policy guidance (including the National Service Framework) and workforce development strategies. These can be used to justify the importance of service user and carer involvement as a priority.
2. Find (or recruit) 'champions' who have the experience, links and personal commitment and support them in working up proposals and leading change within course teams. Alternatively, employ service user or carer consultants to facilitate the development process.

4.2 How to get started – one approach

For those programmes which have yet to involve service users or carers, making the first step can seem quite daunting. Other programmes may have made some progress but have run out of momentum. Here are some suggestions:

1. Set up a Steering Group to devise and implement a strategy that is tailored to the specific needs to the course and the locality. To be effective, such a group may need to comprise:

- a senior representative of the management of the course (perhaps the Head of School, Academic Dean or Training Manager). It may help in terms of freeing up their participation in the process if this person does not automatically have to take on responsibility for chairing the group.
- members of teaching staff who are particularly enthusiastic about championing service user and carer involvement
- service users and carers – drawn from a local group or forum, or via personal networking

Practice educators and student representatives may also be involved

It is likely to work best if there are roughly equal numbers of management / staff and service user / carer members. For service users and carers, the 'Noah's Ark' principle can be crucial – being the lone voice among a sea of unfamiliar faces can be a particularly disempowering experience. Therefore having one or two interested 'reserves' can be very useful so that they can step in if someone is unwell or otherwise committed.

2. Before working up a strategy, it can be important to discuss and agree the basic 'groundrules' which will underpin how people will work together. These may include:

- a commitment to value equally everyone's expertise, whether it is derived from experience as an educator or from direct experience of living with mental distress
- a commitment not to use power positions within hierarchies or organisations as a basis for forcing through decisions or making it appear that certain opinions or perspectives are more valid than others
- agreeing language that feels comfortable to everyone to use. This may involve giving permission to challenge any form of 'jargon', and any terms which individuals might find demeaning or oppressive (and this may include commonly used terms such as 'personality disorder'). However, it must also be recognised that getting too hung up on 'politically correct' language can get in the way of making progress on substantive issues.

3. In devising a strategy, it may be helpful both to identify longer term goals and some shorter term 'easy wins' – some changes that could be implemented relatively easily in order to start the ball rolling, such as identifying particular teaching sessions or modules where user and carer involvement could be particularly valuable. It may also be helpful to identify what may be specific barriers to change (e.g. budgets), and explore how these may best be overcome within the local context.

4. Employing service user or carer consultants to work with a programme may be particularly effective in breaking down certain sorts of barriers – particularly where there is a need for attitudinal change, or for more information about how things might be done, based on experience elsewhere.

5. In time, the Steering Group – in terms of its range of representation and its way of operating - may provide a prototype on which to base more inclusive management structures for the programme as a whole.

4.3 Representativeness and diversity

Historically, one way in which individual service users and carers have been disqualified by powerful vested interests is to argue that they are not representative because they are somehow not like 'typical' service users or carers (perhaps because they have found the confidence to speak up for themselves). This test of representativeness is discriminatory as it is not applied to other potential contributors – a social worker does not usually have to justify that they are representative of social work in general in order to be allowed to offer their input.

Increasingly, service users and carers are able to base their contributions, not just on their own experience but also on the findings from user and carer research, a growing literature of personal accounts, and by actively finding out about others' experiences, for example by liaising with patients' forums and carers groups.

However, often without realising it, certain service user and carer organisations can tend to encourage one 'sort' of user or carer viewpoint rather than another, thereby implicitly discriminating against those whose experiences may differ from the majority.

Research shows how wider forms of social inequalities impact on the mental health field (Pilgrim and Rogers, 1999; Tew, in press). Women, people from Black and minority ethnic communities, and lesbian and gay people may be more likely to be diagnosed with mental health difficulties. They may also be treated in ways that are experienced as particularly oppressive or disrespectful, and which ignore their specific needs and identities. As a consequence, such groups may be more reticent about becoming involved in education and training – and are also often under-represented within local service user or carer groups.

Similarly, within the mental health system, there can be particular stigma attached to particular diagnoses – so, for example, people with 'personality disorder' may have been made to feel unwelcome within services, and also potentially within service user groups.

What is essential is to work towards setting up networks and structures that support all sorts of service users and carers to become involved, particularly reaching out to those whose voices may tend to be excluded (see Section 4.5). This may involve working with (or setting up) specific support groups or networks for those groups who may otherwise feel excluded or alienated from the mainstream, and giving them the confidence that their experience will be valued by courses and by students.

4.4 Changing the culture of a course

While the popular image of higher education and professional training may be one of opening minds and exploring potential, it can come as quite a shock for service users and carers to encounter structures and institutions which may be strongly hierarchical, with built-in pecking orders. Within such cultures there can be resistance to letting go a little of the 'expert' role.

Similarly, despite their potential access to more enlightened perspectives, educational settings may not always be free of stigmatising or discriminatory attitudes. Service users may be perceived by some as ill (all the time), unreliable or even dangerous. This can be reinforced by a medical/biological model of mental health. Carers may be seen as negative and critical of professionals, or as causing many of the problems faced by service users.

Despite this, there may be members of teaching staff who are profoundly uncomfortable with such exclusionary attitudes, and are looking for internal and external support in changing the culture to one that is more inclusive and welcoming. This can come about through developing working relationships with services users and carers.

Statement of Values

We would recommend that teaching staff and course managers enter into an open dialogue with service users, carers and other stakeholders as to what should be the value base of the programme. This can be seen as a development of the statements of course philosophy that may be familiar within higher education – but one which includes explicit statements of how the expertise of service users and carers is to be valued within the ethos of the programme.

It may be important to draw together academic ideas around educational philosophy with aspirations towards partnership with service users and carers that may be developed in local service delivery organisations, or by local user and carer groups. Useful starting points could be the NIMHE Statement of Values and the work undertaken by the NIMHE/Sainsbury Centre Joint Workforce Support Unit on "Ten Essential Shared Capabilities" (Hope, 2004). It may be better that programmes develop their own Statement of Values, rather than following some external blueprint, as it is the process as much as the final product which develops ownership.

A good values statement will be clear and easy to read, perhaps only one or two paragraphs in length, in order to be easily replicated as a poster, handout or inserted into future documents.

Procedures and Conventions

Particularly in higher education, there are a range of procedures and conventions which may need to be revisited if the perspectives and expertise of service users and carers are not to be marginalised or excluded. This may apply, in particular, to the conduct of:

- validation / revalidation of courses
- accreditation / reviews of courses by professional bodies
- examination or assessment Boards
- forums for course management

Viewed from the outside, many of these can seem to operate in ways that are somewhat arcane and overly bureaucratic; perhaps with complex forms of point-scoring that do not seem to relate to the real issues, or collusive processes which prevent certain issues being aired. Just being invited to join as a representative in existing meetings and processes can feel dispiriting and excluding to service users and carers, and can be ineffective in providing proper scrutiny from a service user or carer perspective.

Therefore, within such forums and structures, decision making processes may need to be made more transparent and open, and appropriate ways need to be devised of involving service users and carers as partners. Such changes may be of benefit to all participants and result in more effective scrutiny and decision making.

Involvement in programme validation

At the University of Central England, service users were involved in validation of the social work programme. Some were involved in preparing the course documentation, whilst others were recruited from service user organisations as members of the validation panel, along with representatives from the University, both external to and within the faculty from which the course to be validated originates. Panel members play the role of "critical friend", reading and constructively criticising course documentation. Service users were felt to have had a very valuable role to play in this process – raising concerns about terminology for example, resulting in greater conceptual clarity for students. It is intended that carers as well as service users will be represented in any future validation processes. Contact: Robert Dolton **robert.dolton@uce.ac.uk**

Enabling teaching staff to own progress towards service user and carer involvement – and engage in changing attitudes and practices

People generally do not respond well to being told that they have got it all wrong, or to having a new way of thinking imposed upon them. Effective change tends to occur when people are enabled to find new ways forward that work for them and build on aspects of their existing knowledge, experience and expertise. If new ways of working are owned, they are more likely to be sustained and developed.

A very practical way forward may be to arrange developmental sessions, or even 'away days', for course teams. It may be helpful to employ service user or carer consultants as facilitators for some of these. Options include:

- initial sessions to provide an opportunity for teaching staff to explore and share their aspirations, while also identifying particular anxieties or barriers to progress.
- 'getting to know each other' sessions in which teaching staff, service users and carers join together in exercises that help them to get out of prior roles and encounter each other as human beings. For this to work wellthere needs to be a sense of safety for all participants. A degree of fun, as well as more serious dialogue is also helpful.
- task based sessions for teaching staff, service users and carers – for example working together to produce a Statement of Values
- ongoing reviews of progress, perhaps using the National Continuous Quality Improvement Tool (see Section 5.3), to value what has been achieved and identify both next steps and longer term goals.

Course teams may find themselves under pressure to develop in response to other requirements or opportunities – e.g.developing structures for interprofessional learning, moving over to problem or enquiry based approaches, or developing a new curriculum in line with the changing requirements of professional bodies. Rather than seeing service user and care involvement as an unhelpful distraction in the face of such challenges, one can choose to see it as a key resource in meeting them.

4.5 Building capacity for service user and carer involvement

What is already going on in the area?

Trusts, local authorities and, more recently, NIMHE Regional Development Centres (in England) have played an active role in promoting, co-ordinating, supporting and developing service user and carer involvement in mental health services at all levels.

A capacity building initiative

In the North West of England an initiative is underway to share best practice in the involvement of service users and carers in mental health training and develop a network of people interested in an inclusive approach to training and education.

Contact: Janice Horrocks
janice.horrocks@nimhenorthwest.org.uk

This is often achieved through establishing local service user and carer forums, which may be supported by paid workers who may have direct experience as users or carers themselves.

Forums carry out many functions which vary from locality to locality. They may be able to:

- provide access to service users and carers to support the development of the course
- provide a link between the wider body of service users and carers and those who become involved in training and education
- provide ongoing links that encourage new service users and carers to become involved with the course
- support service users and carer led education and research initiatives.

Alongside such forums, there may be a range of local organisations run by, or in partnership with, service users and / or carers, such as:

- campaigning and media groups
- self help organisations such as Hearing Voices Networks, Manic Depression Fellowship, etc
- voluntary / independent sector service providers, such as local MIND or Rethink groups
- groups and networks providing research, training and / or consultancy

Even in areas where there has been a lot of activity, service users and carers experienced in training may become 'the usual suspects', approached to be involved in everything.

In many localities, service user involvement in mental health services is as yet more fully developed than carer involvement, with more of an existing infrastructure to support it. However, in some localities, the reverse may be true.

Whatever capacity may have already been developed in a given area, there is likely to be a large untapped resource of people who would potentially be interested and have a lot to offer, but who are not connected to any existing group or network.

Finding out and making contact

Educators may get best results by approaching existing forums and groups on their own terms, perhaps asking to attend as a visitor and giving a presentation about what they aim to achieve by involving service-users or carers. Some knowledge of local politics within the networks can be helpful in smoothing the process of building up contacts.

It is important to recognise that people involved in existing organisations and groups may not have seen involvement in education and training as a major priority or interest. Many will have a commitment to improving services or changing attitudes, but may not have thought that they could make a direct contribution to professional education as a way of achieving this. Even if members of a group are not personally interested in education, they may know of others who would be – so existing organisations can be a source of good networking opportunities.

When making initial contact

- invite people to 'dip their toe in the water' – perhaps to meet for an informal discussion before discussing any further commitment
- be prepared to meet with people on their territory and respect their interests, agendas and aspirations
- be clear about payment for time and expenses

Reaching out to new people

Some courses have tried advertising in the local media to attract service users or carers who may not be linked in to existing groups or organisations. This has tended to have limited success as a one-off strategy, but may have more potential if linked to a series of news features on mental health issues and service user and carer involvement. That might raise awareness and interest, and promote a positive sense of what service users and carers have already achieved.

More successful strategies tend to be based on personal contact and word of mouth communication. Approaches may be made through assertive outreach teams, day services, voluntary organisations, and so on. Practitioners can be invited to raise the idea with service users or carers they are working with, or it may be possible to convene open meetings at venues that are comfortable for service users or carers – perhaps resource centres or local community facilities.

Many trusts and social services departments have mailings which can be used to send out flyers or posters inviting service user and carer involvement. Flyers should emphasise that expenses will be reimbursed, that people can be paid for their time in ways that do not affect their benefits, and that support, training and opportunities for skill development will be offered. A small event, to welcome all those interested and give them the chance to meet each other may be appropriate.

In reaching out, it may be important to target groups of service users or carers whose voices are under-represented, such as people from Black and minority ethnic groups, lesbian and gay people and others. Specific strategies may need to be adopted, for example working closely with community organisations lesbian and gay switchboards or advice services.

Teaching staff can be hard to get hold of, so people will need to know how best to make contact. We suggest that direct line numbers are given - if possible, with times when the contact person will actually be there. Any voicemail or answering machine should give the contact person's name and, if possible, a warm greeting in their own voice. Please follow up calls quickly as people may quickly lose interest or confidence.

4.6 Funding

It must be recognised that effective service user and carer involvement will have funding implications, particularly in the short term while capacity is being developed and infrastructure put in place. This issue is starting to be acknowledged at government level; for example, the Department of Health is currently providing a limited amount of funding earmarked to support user and carer involvement in the new social work degree in England.

In the longer term, there may be potential for limited savings. Some 'conventional' teaching staff may be freed up for other duties as service users and carers provide more input. Set against this will be the cost of providing a support and training infrastructure to sustain service user and carer involvement, and to bring on new people as current contributors move on. Overall, there is likely to be a need for some recurrent increase in funding.

4.7 Infrastructure for support, training and supervision

It is possible that some service users and carers will already have relevant experience in education or training – or in other fields such as advocacy work which have provided transferable skills. Such people may be able to 'come up to speed' relatively quickly and slot in to teaching teams where these are ready and willing to work alongside service users and carers on a basis of partnership and equality.

At Levels 2 and 3 of the Ladder of Involvement (see Section 5.3), such an approach may just about suffice – although programmes may find themselves increasingly reliant on a limited pool of contributors, with the potential disadvantages that brings.

For programmes that are aspiring to develop further towards Levels 4 and 5, it is crucial to establish the necessary infrastructure to:

- develop capacity – so that sufficient numbers of service users and carers can be recruited to enable wider representation of minority perspectives and become less reliant on the willing few.
- achieve sustainability – to continually bring on new people to take the places of those who, for whatever reason, decide to move on.

For the majority of service users and carers, entering the world of education and training will be a new departure. The impact of mental distress, the social stigma attached to it and, for some, the responses they have received from mental health services, may have resulted in low levels of confidence; and perhaps also unresolved feelings of anger and resentment.

To be effective teachers, people need to develop the confidence that they can be experts, particularly on the basis of this very experience. They also need to learn how they may use their expertise to contribute to students' learning in a variety of ways.

Service Users Involved in Training and Education (SUITE)

South London and Maudsley NHS Trust employs job-share Education and Training Advisors to ensure that service user involvement is embedded in all training delivered and commissioned by the Trust, and at all levels. This includes ensuring that "professional non-user" trainers embed a user perspective (informed by consultation with users, user-focused research user writings, videos and creative work) in their part of the training, to consolidate and validate the users' contributions. The work is carried out under the auspices of SUITE (Service Users Involved in Training and Education), established in May 2003, which also provides a Training the Trainers course. Contact: Steph McKinley **stephanie.mckinley@slam.nhs.uk**

Alongside this, teaching staff need to develop their awareness of the potential of service users and carers, and their skills in nurturing and encouraging this. They also have a crucial role in establishing, and modelling to students, a value base of respect and partnership. Failure to do this will leave service users and carers feeling vulnerable and under-valued, and students less likely to take their contributions seriously.

More specifically, people are likely to need:

- personal support, encouragement and help to develop confidence
- skills training – from basic assertiveness to how to deliver a presentation or lecture
- specific knowledge relevant to the educational process, including different approaches such as problem based learning.
- opportunities for de-briefing, feedback and supervision, especially when they are involved in direct delivery or supporting practice learning. This may be particularly important if there are instances of hostility or overt conflict between students and service users or carers, or where sessions trigger other strong emotions.

This may be enabled in a variety of ways, possibly in combination:

- Supporting and facilitating peer support groups and networks
- Providing train-the-trainer programmes – possibly leading to some form of accreditation
- Mentoring or 'buddying' for new recruits with more experienced user / carer trainers or members of teaching staff.
- Service users or carers working in pairs to offer each other mutual support and feedback.
- Supporting service users and carers in accessing mainstream educational provision to gain skills and qualifications relevant to training and adult education (e.g. City and Guilds adult education qualifications)
- Setting up opportunities for giving and receiving feedback, involving service users and carers, teaching staff and students. These would need to be structured so that all parties feel valued and their viewpoints respected – and could form part of the course (or module) evaluation process.

Remember: A good place to start is to ask service users and carers about their own support strategies – what works for them.

Support / development workers

Teaching staff may not necessarily be the best people to do outreach and capacity building work, or to provide support and training to service users and carers. Much of this may be more effectively facilitated by designated support / development workers; ideally people with direct experience as a service user or carer. A useful exploration of the role of the service user development worker was commissioned by the Northern Centre for Mental Health (Mills, 2003).

Development workers may be directly attached to Higher Education Institutions or training providers, as at Napier, or they may be community based and linked to local service providers, voluntary organisations and service user or carer run organisations.

At a regional level, in England, most NIMHE Regional Development Centres have designated workers with responsibility for developing service user and carer involvement. They may be able to offer support and ideas - and possibly also useful networks for support and development workers in educational settings.

A Strategy for involvement

The School of Community Health at Napier University in Edinburgh has a user and carer involvement strategy. A development worker has been appointed to support and train users of mental health services and carers who contribute in partnership to design and delivery of the curriculum for pre-registration nurses. The Partnership process recognises that service users and carers and service providers are best placed to say what qualities and skills mental health nurses require and should therefore work together with lecturers in the design and delivery of the curriculum. Partners are involved in all stages of the planning process, decisions are made jointly and reviews and changes are undertaken jointly. Service users and carers are involved in nurse education indirectly (materials, written accounts),as recipients (observers, learners in the classroom), directly (trainers, assessors) and strategically (planning). Development of a "partnership agreement" is being explored and, recognising the challenge of taking account of a range of different interests and perspectives, external supervision for the worker has been built in.

Contact: Lynne Edwards
l.edwards@napier.ac.uk

Preparation and support for training

Here are some initiatives which aim to prepare service users and carers to become involved.

SUITE runs a "Training the Trainers" initiative, commissioned by South Maudsley Mental Health Trust (SLAM) Training and Education Department and accredited by the Open College Network (OCN). The course content, length of session and regularity is decided by the users/carers themselves and facilitated by user trainers. The overall aim is to encourage participants to design a course that is specific to them and then to run it (with payment) for staff or users. Contact: Steph McKinley **stephanie.mckinley@slam.nhs.uk**

Anglia Polytechnic University has a long history of recruiting, preparing and supporting people in training. Regular empowerment sessions are held to get people involved with follow-up training the trainers events. For further information contact Tim Schafer **t.a.schafer@apu.ac.uk**

In Derby, funding has been obtained from the Institute of Leadership in Management (ILM) for development of a qualification entitled "The Award in Health and Social Care Consultancy". This is thought to be the first formal bespoke qualification for service users wishing to become consultants and advisers and was run for the first time in 2004. Contact Mike O'Sullivan **michael.o'sullivan@derbymhservice.nhs.uk**

In response to a request from the Shaw Trust to develop a training course in presentation skills for service users, a programme was developed at the Lincoln site of the University of Nottingham school of nursing (Hanson & Mitchell, 2001). This has now run several times, equipping people with presentation skills and the ability to negotiate a training brief. For more information contact Brenda Rush **brenda.rush@nottingham.ac.uk**

The Distress Awareness Training Agency (DATA) set up the Experts by Experience Trainers Forum runs a training the trainers course for service users who practice their skills on the induction programme at Manchester mental health and social care trust. Contact: Rose Snow **rosesnowuk@yahoo.co.uk**

In the West Midlands the SURESEARCH service user network, along with various members of staff from the University of Birmingham, provides training for people to be involved in education and research. For more information contact Ann Davis at **a.davis@bham.ac.uk**

Training for Trainers (T4T) is an innovative resource aimed at equipping more people, including service users and carers, with mental health training skills. It is available from the Mental Health Foundation Mental Health Trainers Network website: **www.mhtn.org.uk** and from Pavilion Publishing **www.pavpub.com**

4.8 Employment and contracting

Ad hoc and temporary arrangements between programmes and individual service users or carers may be a necessary first step along the road to involvement. However, if this involvement is to become credible and sustainable, it needs to be put on a firmer and longer-term footing. Two models have emerged for doing this.These are not mutually exclusive:

Model 1: direct employment of service users and carers

From the point of a service user or carer, being offered a permanent position as a member of teaching staff can be potentially attractive, particularly if there can be flexibility around working hours.

Advantages:

- Equal status with other members of the teaching team
- Access to all the resources of the institution (e.g. research infrastructure, libraries and IT services)
- If more than one person is appointed, there may be opportunities for mutual support
- Continuity. No need for a programme or service user group to scrabble around each year to find who is available to contribute
- Opportunities for sustained development of skills and confidence

Potential drawbacks:

- Harder to sustain the independence of service user and carer viewpoints – there may be a danger that they become absorbed into the culture and attitudes prevailing within the institution
- Some people may need periodic time off in order to manage their mental distress or care for others, and it may be hard to predict when that will be. This can be hard to manage within conventional employment contracts – but is not impossible given some goodwill and creativity. For example, it may be possible to have flexible part time contracts which offer a regular income and specify the total number of days to be worked per annum, but allow days to be 'banked' to allow for periods of time off as required.
- The institutional environment may not offer the sort of support and supervision that people need, and this may contribute to people's mental health difficulties. (N.B. These issues may impact similarly on other members of teaching staff – so action to address this may be of benefit to all)
- Service users and carers may still feel that they are treated as 'second grade' members of staff

It has been recognised that some service users and carers recruited to work in mental health services, or in mental health education, have faced particular stresses and difficulties, such as lack of support, isolation, continually having to fight in order to have their viewpoints heard, or simply being deluged with more work than they can cope with. The publication 'Stronger than Ever – a report on the first national conference of survivor workers' (Snow, 2002) suggests some ways of overcoming barriers in this area.

Model 2: contracting with independent user / carer or voluntary organisations, or with self-employed service users and carers

In order for investment in the training of service users and carers to be worthwhile, both from the point of view of the people concerned and those who may have funded their training, then longer term rolling contracts offer considerable advantages. Without such a guarantee of continuity, people may be reluctant to make the effort in the first place, or may drop out as soon as there is uncertainty as to when the next teaching opportunity will arise.

Advantages:

- Maintains independence of service user and carer viewpoints
- Flexibility in allowing individuals to contribute on a basis that suits them – from offering a few days each year to having much more intensive involvement
- Opportunities for contributors to arrange cover for each other if they feel unwell or need to care at short notice – especially if they are part of training groups or networks

Potential drawbacks:

- Less reliable source of income – a crucial factor for some service users and carers who may be considering whether or not it is financially safe for them to come off benefits
- Service users and carers may still feel like 'outsiders' who lack equality or status
- Institutions may be less ready to offer access to learning resources
- Service users and carers who are skilled at contributing to teaching and learning may not always feel competent in relation to administration or accounting – whether in terms of managing self-employment or co-running a training group

Rather than expecting individuals or collectives to manage their own financial administration, it may be helpful to see if this function can be taken on by an existing voluntary organisation with the relevant accounting, contracting and payments infrastructure, and willing to host such activity as part of their wider charitable purpose.

4.9 Payment, expenses and other practicalities

Whatever the level of involvement, is essential that service users and carers are paid appropriately for their participation. Payment should be made for all types of involvement - not just direct delivery, but also attendance at consultation and planning meetings. In determining what would be a fair rate of pay, the following guidelines may be helpful:

- If the payments are for attendance at meetings or consultation events, presentations, consultancy or training events, it would be appropriate to pay the same rate as would be offered by Trusts and local authorities for similar work. Indicative scales for such payments have been produced by NIMHE West Midlands (2003).
- Where service users and carers are contributing directly to teaching and learning – in developing materials, direct delivery or assessing students' work – they should be paid on the same basis as other external contributors. Higher Education Institutions tend to have a standard Visiting Lecturer hourly rate.

In order to encourage people to come forward for "training the trainers" and other preparatory initiatives, it may be helpful to offer a small payment for their time as well as covering their expenses.

Making payments

There may be practical problems around making payments to service users and carers for both the institution and the individual concerned. For all contributors, it is important to make claiming payments as straightforward as possible, and this may entail working closely with finance departments to develop new procedures:

- Devise a simple form that people can fill in, rather than asking for an invoice
- Do not automatically deduct income tax and require people to claim it back if they are self-employed or below the minimum earnings threshold - instead offer the option of a disclaimer which the contributor can sign to take responsibility for their own tax and National Insurance. (N.B. This may not be possible for those who are making regular contributions throughout a course. Institutions may require such people to have a contract of employment and to receive payment through the normal payroll system).

For those who have chosen to become self-employed or to work as part of a training group, it can be vital to ensure that claims for payment are turned around quickly – failure to do this may result in people having to give up and go back on benefit.

Users and carers often rely on benefits. Many report the benefit system to be inflexible and unpredictable. To avoid uncertainty and potential loss of benefit, they may prefer that weekly earnings are set below the figure that their particular benefits allow them to earn (this may vary from £20 per week to as much as £72 per week).

At a National level, the inflexible and potentially punitive response of the benefits system towards those who are not capable or ready to undertake full-time work has been recognised as a major issue that prevents people with mental health difficulties undertaking work on a more limited and flexible basis. It is most unfortunate that this has not been adequately addressed in the Government's report on Mental Health and Social Exclusion (Office of the Deputy Prime Minister, 2004). This is likely to remain the greatest single impediment to building the level of capacity among service users and carers necessary to deliver the Government's own vision for professional education and training in mental health.

For those who are reliant on benefits, it may be helpful if certain practical strategies can be adopted. For example:

- Instead of paying out one lump sum for a piece of work (which may exceed a person's permitted earnings threshold for a week), spread the payments over a longer period – e.g. paying for preparation time on a weekly basis, rather than including this as part of an invoice on completion of the work
- Some people prefer that payments do not go to them individually, but to a local group or a voluntary organisation of their choice.

Such strategies may require careful preparatory work with finance departments. Any institution which seeks to involve people who are vulnerable and who rely on benefits as their sole income has a duty of care – so it is important to liaise with local tax and benefit offices to ensure that arrangements do not cut across regulations, and ensure that no service users or carers run the risk of losing their benefit entitlements (and/or prosecution for fraud) through agreeing to contribute to a programme. It may be helpful to work closely with colleagues in other disciplines or in other institutions locally in order to share practice and arrive at common approaches.

For a fuller discussion of these issues and practical advice, see Scott (2003) and Levin (2004). Listed below are policies that have been developed by some organisations – but we cannot confirm that these comply with all current and future regulations. In developing local policies, IT IS IMPERATIVE THAT THEY ARE CHECKED OUT WITH LOCAL BENEFIT OFFICES.

Expenses

Many service users and carers are surviving on benefits or low incomes. Whatever practice is established in relation to making payments, one vital practical step is to develop the facility to pay people's expenses in cash on the day that the expense is incurred. Without this, people may find that they cannot turn up at a meeting or a teaching session because they simply cannot afford the bus fare on the day.

Again, this may require negotiating with finance departments new rules and procedures for the disbursement of petty cash.

Travelling

Some service users and carers may have particular difficulties in relation to travelling. They may need someone to travel with them or they may be unable to use public transport and need a taxi – so the flexibility to pay additional expenses may be required. For those who drive, thought may need to be given to the availability of free parking spaces close to the teaching or meeting room.

Recruitment, selection and contracts

In the first instance, it is likely that recruitment will be via personal contacts, word of mouth and any databases of service user and carer trainers. held locally

However, particularly if service users and carers are being recruited to substantive teaching posts or employed on regular contracts, it becomes important to institute fair and open processes for selecting people for particular roles, based on a clear specification of what is required, with due attention paid to ensuring equality of opportunity.

In order to give opportunities to new people entering the field as well as those who are more established, it is helpful to specify a range of roles which service users and carers can undertake, some more demanding of experience and prior training than others.

Where service user or carer input is via independent training groups, this needs to be on the basis of contracts, which clearly specify expectations and responsibilities of both parties. Ideally, contracts should be for more than a year, with a built in process for evaluation and renewal – and a facility to terminate the contract if either party is not able to deliver what was agreed at the outset.

Paying people to be involved

Three examples of policies relating to payment for involvement come from:

Nottinghamshire Healthcare NHS Trust Contact **tracy.holmes@nottshc.nhs.uk**

NIMHE West Midlands Contact: **barbara.crosland@nimhe-wmids.nhs.uk**

NIMHE Eastern Contact: **reg.mckenna@ntlworld.com**

Hull and East Riding Community Health NHS Trust has produced a code of practice for paid service user and carer involvement in mental health services.

Contact: Bill Davidson **sirwillcock@aol.com** or Diane Heywood **diane.heywood@herch-tr.nhs.uk**

Most of the initiatives referred to in this guide have experience of developing systems for payment of users and carers.

The Faculty of Health and Social Care at the University of the West of England has for some time had a procedure for paying users and carers who contribute. Programme staff work closely with a local user/voluntary organisation to recruit user-trainers and payment is made through that agency. For further information contact Stewart Dewer **stewart.dewer@uwe.ac.uk**

The Richmond Fellowship employs a range of service user trainers on its Diploma in Community Mental Health course at Middlesex University, with well established procedures for payment. For more information contact Peter Allen **peter.allen@richmondfellowship.org.uk**

4.10 Checklist for service users and carers preparing to become involved

The following checklist (based on one devised by Premila Trivedi, an experienced user trainer) may be useful to give out to all service users and carers as part of their preparation for involvement in a programme. It can be amended to take account of local differences and whether it is being distributed by the institution itself or by a service user or carer group.

Looking after yourself and making a difference

A checklist for service users and carers preparing to become involved in mental health education and training

1. Recognise your own expertise, and all the skills and talents you as an individual can bring. Believe in yourself and what you are trying to do.
2. Allow yourself time to build up your confidence and skills – start small and grow gradually.
3. If possible, work alongside another service user or carer or have someone else you trust there to support you.
4. Have you got support systems in place? Are you able to get support from friends and allies, or from service user or carer support groups and networks? What support is being offered to you by the programme, and is this enough?
5. Don't let the professionals over-use you – it's your right to say no.
6. Only contribute to education and training if you get something out of it.
7. Be aware of issues of (in)equality and diversity and try to make sure that the experience of members of different minority groups is not overlooked.

If you are involved in planning and/or delivery of teaching or in programme management or evaluation:

8. Think what it is that you want students to learn. Decide what key messages or learning points you are trying to get across (it's very easy to get side-tracked!)
9. Think carefully and discuss with other members of the course team how best to get these messages across – e.g. research evidence, people's stories, interactive exercises and role plays, sharing your own experience.
10. Be clear about which personal experiences you are prepared to share with students in order to facilitate their learning (and which not!) - and try to stick with that. Don't be pressurised into discussing things which don't feel safe for you.
11. Spend time planning and preparing so you are clear and confident about what you want to contribute
12. Anger is OK and necessary sometimes, but try and stay focused - remember your involvement is about encouraging people (students and teaching staff) to change their practice – not about having a go at them!
13. Don't beat yourself up if you have an off-day or if you feel you did not perform very well.
14. Don't beat yourself up if people become defensive, don't listen, remain inflexible or are just plain ignorant! You can't change the world all at once. Be willing to reflect on how you might (or might not) wish to do things differently next time.

If you are involved in student selection or assessment:

15. Think about what values, attitudes, personal qualities, knowledge or skills you would expect students to be able to demonstrate. Discuss these with other members of the course team (don't let yourself be fobbed off if you think something is important).
16. Think carefully and discuss with other members of the course team how best to assess these.

Everyone:

Are you clear what you are being invited to do, how much you will be paid for it, and how your expenses will be reimbursed? If you rely on welfare benefits, have you had advice as to how any earnings may affect these? Do you need help with arranging care or any other practicalities?

5 Evaluating Progress

In order to reflect on the level of service user and carer involvement a particular programme has achieved, and what could be the next stage in its development, it may be helpful to evaluate progress in a systematic manner. Many courses will be conducting evaluations using the National Continuous Quality Improvement Tool for Mental Health Education (NCMH, 2003) – and this Guide is intended to be used alongside it in relation to service user and carer involvement. The Ladder of Involvement and the scoring system outlined here may also be used separately if this is more appropriate.

While this Quality Improvement Tool is likely to be used mainly within higher education, other providers of training and education may also find it helpful. It is designed to promote a constructive process of dialogue and discussion, both within course teams and more widely with other stakeholders involved with a programme, to see how relevant a course may be to meeting the challenges of preparing students to work in a modern mental health service. It encourages honest self-evaluation of progress in relation to local circumstances.

This Guide may be used in conjunction with the Quality Improvement Tool in helping to frame the agenda for internal course reviews and planning forums, and for wider stakeholder events. Within such events it must be recognised that courses may not always be in a position to advance in isolation. There may be issues of developing capacity among service users and carers that can only be tackled through joint strategies involving education providers, service providers, user and carer organisations, Workforce Development Confederations / Strategic Health Authorities and NIMHE Regional Development Centres.

5.1 The experience of service users and carers

Based on Premila Trivedi's 'Involvometer', we offer a simple questionnaire to check out how service users and carers may have found their experience of involvement.

Service user and carer experience of being involved in Mental Health Education and Training

Instructions
Which area(s) of work you been involved in (please tick)

- ☐ Direct delivery of learning and teaching
- ☐ Course / module planning
- ☐ Programme management
- ☐ Recruitment and selection of students
- ☐ Practice learning
- ☐ Student assessment
- ☐ Course evaluation
- ☐ Other

Now, consider each of the statements below and score each on a scale of 0-5, where:

0 = not at all **1=a little bit** **2=sort of**
3 =acceptable **4=good** **5= definitely**

Before

1. I received full information before starting the work. .....
2. The information was easy to understand and all jargon was explained. .....
3. It was clear why they wanted me to be involved. .....
4. I had a useful meeting with the co-ordinator (or other member of the teaching team) before starting the work. .....
5. All practical details, e.g. payment, access needs, support etc were sorted out before the work started. .....

During

1. The work was interesting. .....
2. It felt OK to ask when something was not clear or when I was getting lost. .....
3. The room/setting felt comfortable and not intimidating. .....
4. The other teaching staff were polite and friendly towards me. .....
5. The other teaching staff treated me with respect and listened to my views. .....
6. It was possible to disagree with the other teaching staff and still to feel OK. .....

7. The students were polite and friendly towards me. .....
8. The students treated me with respect and listened to my views. .....
9. It was possible to disagree with the students and still to feel OK. .....
10. I felt my input was being taken seriously and I was having an effect. .....
11. I knew whom to go to for support if there were any difficulties. .....

After

1. I had the chance to discuss the work and how I felt it had gone when it was over. .....
2. I felt my contribution made a difference. .....
3. I received balanced and constructive feedback in relation to what I had contributed. .....
4. If I received payment, I received it simply and quickly. .....

NOW add up all your scores and see how positive your particular experience of Service User and Carer Involvement was!

TOTAL SCORE = ...

0-25	=	unacceptable – urgent action required
26-50	=	adequate – but need to look at making the experience better
51-75	=	good
76-100	=	excellent!

Please include anything else you would like to tell us, or anything that you would like us to pass on to the programme concerning service user and carer involvement.

5.2 The experience of students

Along similar lines to the 'Involvometer', a simple questionnaire for students would provide useful evaluative feedback.

Student Experience of Service User and Carer involvement in Mental Health Education and Training

Instructions
In which aspects of your learning have service users and carers been involved (please tick)

- ☐ Direct delivery of learning and teaching
- ☐ Recruitment and selection of students
- ☐ Practice learning
- ☐ Assessment of student work
- ☐ Other

Now, consider each of the statements below and score each on a scale of 0-5, where:

0 = not at all **1 =a little bit** **2 = sort of**
3 = acceptable **4 = good** **5 = definitely**

Before

1. I was informed in advance that service users and carers would be involved in delivering or participating in the course. .....
2. It was explained to me why service users and carers would be involved. .....
3. User and carer involvement fits with the overall philosophy and values of the course. .....
5. All practical details, e.g. payment, access needs, support etc were sorted out before the work started. .....

During

1. I felt that service users and carers were treated with respect and were listened to. .....
2. I felt that service users and carers treated me with respect and were willing to listen to my point of view. .....
3. I felt their input was being taken seriously and was having an effect. .....
4. I enjoyed my contact with service users and carers on the course. .....

After

1. Through their involvement in the course, I have come to see service users and carers as people who have a lot of valid knowledge and ideas. .....
2. Having service users and carers involved has given me new insights, knowledge and understanding. .....
3. Having service users and carers involved has changed the way I will work in my practice. .....

NOW add up all your scores and see how positive your particular experience of Service User and Carer Involvement was!

TOTAL SCORE = ...

0-25	=	unacceptable – urgent action required
26-50	=	adequate – but need to look at making the experience better
51-75	=	good
76-100	=	excellent!

Please include anything else you would like to tell us, or anything that you would like us to pass on to the programme concerning service user and carer involvement.

5.3 The Ladder of Involvement

In some instances, especially when setting up a new programme, it may be possible to embed full-scale service user and carer involvement in all areas from the start, together with the infrastructure necessary to support this. More usually, especially when developing involvement within existing programmes, it may be more realistic to start with smaller scale initiatives and work progressively towards greater service user and carer involvement.

Whichever approach is taken, it may be helpful to be able to rate progress in relation to the Ladder of Involvement (see over). Based on a framework adapted from Goss and Miller (1995), this underpins the evaluation processes set out in the National Continuous Quality Improvement Tool for Mental Health Education.

In Sections 2 and 3 of the Quality Improvement Tool, service users and carers who are involved with the course are each invited to give the course a score for, respectively, service user and carer involvement. It is hoped that the scoring will arise out of reflection and dialogue involving members of the teaching team and course management - but it is ultimately for service users and carers to decide on the appropriate score.

In broad terms, moving one step up the ladder merits an additional score of 5, up to a maximum score of 20 corresponding to full partnership. This provides a clear and simple basis for rating the stage that a course may have reached, and hence identifying what may be the next stage of its development.

Please note:
The version of the Ladder shown overleaf has been developed from that included in the first edition of the Quality Improvement Tool. Following a piloting phase, the Tool is currently in the process of revision. For further details contact **ian.baguley@trentconfed.nhs.uk** *Tel 01623 819370.*

LADDER OF INVOLVEMENT

LEVEL 1: NO INVOLVEMENT

The curriculum is planned, delivered and managed with no consultation or involvement of service users or carers.

LEVEL 2: LIMITED INVOLVEMENT

Outreach and liaison with local service user and carer groups. Service users / carers invited to 'tell their story' in a designated slot, and/or be consulted ('when invited') in relation to course planning or management, student selection, student assessment or programme evaluation. Payment offered for their time. No opportunity to participate in shaping the course as a whole.

LEVEL 3: GROWING INVOLVEMENT

Service users / carers contributing regularly to at least two of the following in relation to a course or module: planning, delivery, student selection, assessment, management or evaluation. Payment for teaching activities at normal visiting lecturer rates. However, key decisions on matters such as curriculum content, learning outcomes or student selection may be made in forums in which service users / carers are not represented. Some support available to contributors before and after sessions, but no consistent programme of training and supervision offered. No discrimination against service users and carers accessing programmes as students.

LEVEL 4: COLLABORATION

Service users / carers are involved as full team members in at least three of the following in relation to a course or module: planning, delivery, student selection, assessment, management or evaluation. This is underpinned by a statement of values and aspirations. Payment for teaching activities at normal visiting lecturer rates. Service users / carers contributing to key decisions on matters such as curriculum content, style of delivery, learning outcomes, assessment criteria and methods, student selection and evaluation criteria. Facility for service users / carers who are contributing to the programme to meet up together, and regular provision of training, supervision and support. Positive steps to encourage service users and carers to access programmes as students.

LEVEL 5: PARTNERSHIP

Service users, carers and teaching staff work together systematically and strategically across all areas – and this is underpinned by an explicit statement of partnership values. All key decisions made jointly. Service users and carers involved in the assessment of practice learning. Infrastructure funded and in place to provide induction, support and training to service users and carers. Service users and carers employed as lecturers on secure contracts, or long term contracts established between programmes and independent service user or carer training groups. Positive steps made to encourage service users and carers to join in as participants in learning sessions even if they are not (yet) in a position to achieve qualifications.

5.4 Taking all aspects of involvement into account: a more detailed scoring system

As is explored in previous Sections of this Guide, there are a number of distinct aspects to developing service user and carer involvement :

1. Broadening the **scope of participation** into more areas of the educational process, from direct delivery through to programme management, student assessment, and so on (see Section 3)
2. **Inclusiveness** of the course culture – changing the terms of involvement so that in any area of activity, service users and carers are able to become increasingly equal partners, participating in setting the learning agenda and influencing key decisions about direction and outcomes (see Sections 4.1-4.4)
3. Developing an infrastructure to **build capacity** and provide **support and training** for service users and carers who are contributing to programmes (see Sections 4.5 and 4.7)
4. Developing an infrastructure for **employing or contracting** with service users and carers (see Sections 4.8-4.9)

In practice, some courses may find that they do not fit neatly with the descriptors for any one level on the Ladder of Involvement as they are making progress faster in some areas than in others. For instance, in terms of the scope of involvement, a course may be heading towards partnership in relation to course design and delivery, but no progress have been achieved in relation to involvement in assessment. Another course may be exemplary in terms of putting in place the necessary infrastructure for making payments, contracting and providing support and training to service users and carers, but may be struggling when it comes to changing the culture among teaching staff so that there is little effective collaboration within the delivery of teaching and learning.

Therefore, in order for there to be a more comprehensive evaluation of progress across all areas, and for the final score out of 20 to reflect fairly what a course has achieved, some courses **may** choose to adopt a more detailed scoring system that takes these four areas into account. A framework for doing this is set out on the next page – and this may provide a useful set of prompt questions for service users and carers in helping them to work out how they should rate the course.

A More Detailed Scoring System

1 SCOPE OF INVOLVEMENT OF SERVICE USERS AND CARERS

- ☐ Programme management
- ☐ Recruitment and selection of students
- ☐ Course/module planning
- ☐ Direct delivery of learning and teaching
- ☐ Practice learning
- ☐ Student assessment
- ☐ Course Evaluation
- ☐ Service users joining courses as participants

Score of 1 for meaningful involvement in relation to each of these
SCORE: ..../8

2 INCLUSIVENESS OF THE COURSE CULTURE

Select which statement best describes the current level of development:

Service users / carers consulted but decisions made elsewhere	Score 2
Participation in some decision making forums	Score 4
Real partnership based on written statement of values	Score 6

SCORE: ..../6

3 CAPACITY BUILDING, SUPPORT AND TRAINING

Select which statement best describes the current level of development:

Outreach and liaison with local service user and carer groups.	Score 1
As above with some regular training, supervision and support offered to contributors.	Score 2
Ongoing programme of induction, support and training, probably via designated support / development worker	Score 3

SCORE: ..../3

4 INFRASTRUCTURE FOR EMPLOYMENT OR CONTRACTING

Select which statement best describes the current level of development:

Payment at least at recommended rates for meetings and consultation events. Expenses paid in cash on the day.	Score 1
Payment for teaching and assessment related activities at visiting lecturer rates. Short term and temporary contracts only	Score 2
Either users / carers employed on permanent basis or longer term contracts with independent training groups or self-employed trainers.	Score 3

SCORE: ..../3

TOTAL SCORE: ..../20

6 Conclusions and Recommendations

As will be seen from the foregoing discussion, achieving effective service user and carer involvement involves a significant commitment of time, along with relationship building, strategic planning and problem solving skills; and all of this needs to be underpinned by appropriate funding and an infrastructure for support. The potential benefits of providing students with opportunities to learn from the practical knowledge and insight of service users are, however, immeasurable – ensuring that, as future members of the mental health workforce, they are equipped with the necessary values, attitudes and skills and a mind-set of working in partnership.

Beyond this, working in this way offers the potential for more personal benefits, both for teaching staff and for service user and carer contributors. A sense of excitement and a stimulation of ideas can result from processes of dialogue and sharing. This can help teaching staff to keep in touch with current practice issues "on the ground", and encourage a willingness to rethink received wisdom. For service users and carers, the experience of being listened to and taken seriously, and of making a contribution that is valued, can boost self-esteem and help towards recovery.

Although there is already much good practice in this area, initiatives will remain in relative isolation until user and carer involvement can be embedded into the routine processes of commissioning, contracting and management of mental health education and training. It is to be hoped that the National Continuous Quality Improvement Tool, together with this Guide, may contribute towards bringing this about.

Recommendations

1. Programmes should start by devising a clear written statement of partnership values, as an element of their course philosophy, and indicate how these will be applied and upheld. These should be signed up to by all stakeholders and contributors.
2. In dialogue with service user and carers, programmes need to formulate a written strategy for developing service user and carer involvement. This may usefully be shared with commissioners and other stakeholders. Ideally, this should contain an explicit aspiration to work towards developing involvement in all aspects of the programme, including student recruitment, selection and assessment, and course planning, management delivery and evaluation. A designated person should be identified with responsibility for taking this strategy forward. Progress can be evaluated using the National Continuous Quality Improvement Tool for Mental Health Education.
3. Commissioners and/or programmes should identify ring-fenced monies for the development of service user and carer involvement – either by making the case for additional funding or through top-slicing existing budgetary allocations. These may then be used to fund the development of an infrastructure to support service user and carer involvement – perhaps including the establishment of support / development worker posts.
4. Each programme should select a model for supporting user involvement that is appropriate to its needs. This may involve creating staff posts for those with service user and carer experience, or contracting with independent training groups or consultants. Whichever model is chosen, consideration will need to be given to structures to induct, train and provide ongoing support to those service users and carers who become involved in education, and to accrediting such training. Thought will also need to be given to how existing staff can best learn to work effectively in partnership with service users.
5. Priority should be given to developing capacity among service users and carers – encouraging more people to become involved - with a particular focus on ensuring that minority viewpoints are fully represented, such as those of women, members of Black and minority ethnic communities, and lesbian and gay people.
6. NIMHE Regional Development Centres and/or Workforce Development Confederations / Strategic Health Authorities may wish to consider providing (web-based) directories of service user and carer groups and networks; and possibly also lists of service users and carers with experience of contributing to education and training. This would facilitate networking between users and carers involved in training and, together with ongoing opportunities to share examples and experience, could save much duplicated effort by programmes. Similar arrangements could be considered in other parts of the UK.
7. In line with social inclusion strategies (Office of the Deputy Prime Minister, 2004), further progress needs to be made in adapting welfare benefit regulations to make it possible for people with ongoing mental health difficulties to undertake work on a limited and flexible basis without jeopardising their entitlement to benefits. If benefits were reduced simply in proportion to hours worked (if any) each week, rather than a person's entire entitlement to benefits being removed, a far larger number of people would be able to make meaningful contributions to mental health education and training.

Appendix A: the Authors

Jerry Tew is a Senior Lecturer in the School of Social Work at the University of Central England where he has collaborated in setting up joint mental health teaching for social work and nursing students which has substantial input form service users and carers. He is the subject advisor for social work on the steering group of the Mental Health in Higher Education Project (mhhe) and is on the Executive of the Social Perspectives Network for Modern Mental Health which is linked to the National Institute for Mental Health in England (NIMHE) and the Social Care Institute for Excellence (SCIE). He is a member of Moving On, a training group comprising people who have experience of using or working in mental health services, and is an associate of Suresearch.

Colin Gell has been active in service user involvement since 1986. He is a founder member and worker with the Nottingham Advocacy Group, one of the first user-led organisations in Britain. He has worked with a number of organisations developing service user involvement, including the Centre for Mental Health Services Development, Sainsbury Centre, Trent Region Health Authority, University of Birmingham, Mental Health Task Force, Institute of Applied Health and Social Policy at Kings College London and the Direct Payments in Mental Health national pilot. He has recently been involved in the consultation and production of guidelines for service user involvement in the training of the Graduate Primary Care Mental Health workers, and is currently working with NIMHE East Midlands and the Trent Workforce Development Confederation. He is the Co-ordinator for Suresearch network, a Midlands based network of service users involved in research and education.

Simon Foster works for Carers in Partnership, a carer-led initiative supported by NIMHE West Midlands and Rethink. Carers in Partnership promotes the carers' voice in the way mental health services are planned, set up and run in the West Midlands region.

Appendix B: Reference Group

Reference group

The following people provided comment on the first draft of the guide:

John Allcock

Marion Clark

Anne Cooke

Nisha Dogra

Grainne Fadden

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Debbie Green

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Mick McKeown

Damian Mitchell

Penny Morris

Anne O'Donnell

Jane Roe

Wendy Roodhouse

Brenda Rush

Judy Scott

Patience Seebohm

Rose Snow

Premila Trivedi

Susan Walsh

Helen Wenman

Kim Woodbridge

Peter Wright

Publications and References

Please note that a more comprehensive reading list of articles and publications relating to user and carer involvement in mental health is available from the Mental Health in Higher Education website: **www.mhhe.ltsn.ac.uk**

Barnes, D., Carpenter, J. and Bailey, D. (2000) Partnerships with service users in interprofessional education for community mental health: a case study. Journal of Interprofessional Care 14:2 pp.189-200.

Basset, T. (1999) Involving service users in training. Care 7:2.

Bassett, T., Cooke, A. & Read, J. (2003) Psychosis revisited: a workshop for mental health workers, Brighton: Pavilion Publishing

Beresford, P. (1994) Changing the culture: involving service users in social work education. London: CCETSW.

Campbell, P. and Lindow, V. (1997) Changing practice: mental health nursing and user empowerment. RCN Learning Materials on Mental Health. London: Royal College of Nursing.

Carers in Partnership (2004) mhhe Focus Group for Carers 8:12:03: Report of discussions. Redditch: NIMHE West Midlands Regional Development Centre

Carpenter, J and Sbaraini, S. (1997) Choice, information and dignity: involving users and carers in care management in mental health. Bristol: Policy Press.

Coupland, K, Davis, E. and Gregory, K. (2001) Learning from life. Mental Health Care 4:5.

Crepaz-Keay, D., Binns, C. and Wilson, E. (1997) Dancing with angels: involving survivors in mental health training. London: CCETSW.

Department of Health (1999) National Service Framework for Mental Health. London: Department of Health.

ENB (1996) Learning from each other. London: ENB.

Ferguson, K, Owen, S and Baguley, I (2003) The clinical activity of mental health lecturers in Higher Education Institutions. Report prepared for the NHS Mental Health Care Group Workforce Team.

Forrest, S. & Masters, H. (2004) Evaluating the impact of training in psychosocial interventions: a stakeholder approach to evaluation – part 1, Journal of Psychiatric and Mental Health Nursing, 11, 194-201

Forrest, S., Risk, I., Masters, S. and Brown, N. (2000) Mental health service user involvement in nurse education: exploring the issues. Journal of Psychiatric and Mental Health Nursing 7 pp.51-57.

Gell, C (2003) Involving service users in the training of graduate primary care mental health workers. Nottingham: Trent Workforce Development Confederation.

Goss, S. and C. Miller (1995) From Margin to mainstream: Developing user and carer centred community care. York, Joseph Rowntree Foundation.

GSCC/SCIE (2004) Living and Learning Together, London: SCIE

Hanson, B. & Mitchell, D. (2001) Involving mental health service users in the classroom: a course of preparation. Nurse Education in Practice, 1, 120-126

Hastings, M. and Crepaz-Keay, D. (1995) The survivors' guide to training Approved Social Workers. London: CCETSW.

Hope, R. (2004) The ten essential shared capabilities: a framework for the whole of the mental health workforce. London: Department of Health

Levin, E. (2004) Involving service users and carers in social work education. London: Social Care Institute for Excellence.

McAndrew, S. and Samociuk, G. (2003) Reflecting together: developing a new strategy for continuous user involvement in mental nurse education. Journal of Psychiatric and Mental Health Nursing 10: 616-621

McDonnell, F. (2002) Report on Project to involve service users in assessment of candidates for the Certificate in Community Mental Health Care. London: Jewish Care / CCETSW

Manthorpe, J. (2000) Developing carers' contributions to social work training. Social Work Education 19:1

Masters, H., Forrest, S., Harley, A., Hunter, M., Brown, and Risk, I. (2002) Involving service users and carers in curriculum development: moving beyond 'classroom' involvement. Journal of Psychiatric and Mental Health Nursing 9 pp.309-316.

mhhe (2003) Workshop report: Paying more than lip service. User involvement in learning and teaching about mental health in higher education. www.mhhe.ltsn.ac.uk/news/derby.asp

Mills, B. (2003) The role of the service user development worker in the North East, Yorkshire and Humberside, Durham: Northern Centre for Mental Health.

Molyneux, J. (2001) Report on service users' and carer's involvement in the ASW programme. Newcastle: University of Northumbria.

Molyneux, J. and Irvine, J. (2004 forthcoming) Service user and carer involvement in social work training: a long and winding road? Social Work Education.

Morgan, S and Sanggaran, R. (1997) Client-centred approach to nurse education mental health practicum: an enquiry. Journal of Psychiatric and Mental Health Nursing 4 pp.423-434.

NIMHE (2004) The Ten Essential Capabilities for Mental Health Practice: Shared Capabilities for all Mental Health Workers, London: National Institute for Mental Health (England)

NIMHE (2003) Cases for Change: User involvement. Leeds: NIMHE

NIMHE West Midlands (2003) Guidance Paper – Payments of service users and carers. Redditch: NIMHE West Midlands Regional Development Centre.

NCMH (2003) National continuous quality improvement tool for mental health education. York: Northern Centre for Mental Health.

Office of the Deputy Prime Minister (2004) Mental health and social exclusion: Social Exclusion Unit report. London: Office of the Deputy Prime Minister.

Pilgrim, D. and Rogers, A. (1999) A sociology of mental health and illness (2nd ed) Buckingham: Open University Press.

Read, J. (2001) Involving to empower Mental Health Today December 2001.

Reynolds, J and Read, J. (1999) Opening minds: user involvement in the production of learning materials on mental health and distress. Social Work Education 18:4 pp.417-432.

Rose, D. (2001) Users' voices: the perspectives of mental health service users on community and hospital care. London: Sainsbury Centre.

Sainsbury Centre (2000) The capable practitioner. London: Sainsbury Centre.

Sayce, L. (2000) From psychiatric patient to citizen: overcoming discrimination and social exclusion. Basingstoke: Macmillan.

Scott, J. (2003) A fair day's pay: a guide to benefits, service user involvement and payments. London: Mental Health Foundation.

Secker, J., Grove, B. and Seebohm, P. (2001) Challenging barriers to employment, training and education for mental health service users: the service users' perspective. Journal of Mental Health 10:4 pp.395-404.

Snow, R. (2002) Stronger than ever. Manchester: Asylum

Thomas, P. and Bracken, P. (1999) Putting patients first. OpenMind 96 pp.14-15.

Tew, J. (ed) (in press) Social Perspectives in Mental Health: Developing social models to understand and work with mental distress. London: Jessica Kingsley

Tew, J, Townend, M and Hendry, S. with Ryan, D., Glynn, T and Clark, M. (2003) On the Road to Partnership? User Involvement in Education and Training in the West Midlands. Redditch: NIMHE West Midlands Regional Development Centre.

Took, M (1997) Voices of experience: promoting the involvement of mental health service users and cares in interprofessional training. London: CCETSW.

Turner, L., Callaghan, P., Eales, S. & Park, A. (2004) Evaluating the introduction of a pilot client attachment scheme in mental health nursing education, Psychiatric and Mental Health Nursing, 11, 414 -421

Walters, K., Buszewicz, M., Russell, J. and Humphrey, C. (2003) Teaching as therapy: cross sectional and qualitative evaluation of patients' experiences of undergraduate psychiatry teaching in the community, British Medical Journal, vol. 326, p. 740.

Wood, J and Wilson-Barnett, J. (1999) The influence of user involvement on the work of mental health nursing students. NT Research 4 p.271.

Wray, M. (2004) Briefing: supporting students with mental health difficulties – useful resources, Chelmsford: National Disability Team

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