

# Service User/Survivor Involvement in Mental Health Training and Education: Overcoming the Barriers

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*This article discusses 10 barriers to the involvement of service users/survivors in learning and teaching about mental health in higher education, suggesting ways of overcoming each. The paper is addressed to mental health trainers and educators, some of whom will be mental health service users/survivors. We have not looked at the involvement of carers/relatives in learning and teaching here. They also clearly have an important role to play and some of what we have written will have relevance to their involvement.*

*Keywords: Mental Health Services; Barriers; Survivors; Medical Model*

## A MADMAN TEACHING

A madman stands at the blackboard teaching.  
He remembers the doctor had him there,  
Pointing, questioning, silencing him  
With his interpretations.

Bowing ever so slightly  
At his audience.

A madman stands at the blackboard teaching.  
He remembers the nurse putting the needle in,  
Saying it was all for his own good, that he wasn't  
Quite right.

Bowing ever so slightly  
Towards the chargehand.

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A madman stands at the blackboard teaching.  
He remembers that the ward is closed,  
The asylum shuttered.

A madman stands at the blackboard teaching.  
This is our day.  
This is our century.

Peter Campbell

## Introduction

This paper was written in conjunction with participants at a workshop on this topic at the Mental Health in Higher Education project ([www.mhhe.heacademy.ac.uk](http://www.mhhe.heacademy.ac.uk)) event 'Paying more than lip service: user involvement in learning and teaching about mental health in higher education' (held in Derby in June 2003) and has drawn on contributions to workshops at subsequent mhhe events.

The sea-change in mental health services over recent years cannot fail to be recognised by all involved, whether on the receiving end of services, engaged in providing them or, of course, both. There is a growing understanding of the very real contribution that service users can make to developing, or indeed becoming, the practitioners of the future. Yet, it has to be recognised that—whether within services or in educational settings—there are also areas where very little progress has been made. Changing the course of institutions—whether they deliver mental health services or mental health education—can be very hard to do.

The Mental Health in Higher Education project was set up in 2003 with the aim of increasing dialogue and the sharing of approaches to learning and teaching about mental health across the disciplines in UK higher education. Service user/survivor and carer involvement in education has emerged as one central focus of its work. Outputs have included national and regional workshops, a collection of case studies of learning and teaching, network building, a discussion list for Developers of User and Carer Involvement in Education (DUCIE) and the production of a good practice guide, *Learning from Experience* (Tew et al., 2004).<sup>1</sup>

Service users are increasingly involved, across the disciplines in higher education, in planning and delivering teaching; little by little this is extending into engagement in programme management, recruitment and selection, and the assessment of students' work. There is a sense—as expressed in Peter's poem—that their day, their century, has come. Yet, if involvement is to be meaningful and integrated, there are a number of significant barriers to be overcome. This was highlighted at the mhhe workshop, which brought the three of us together. The day, attended by a wide range of academics and service user/survivor trainers, provided a rare opportunity for discussion of these issues across disciplinary divides.

We list below 10 barriers and present, for each, ways of getting around them. In doing this, we draw on the experience both of service users/survivors involved in training, and of lecturers and tutors.

## 1. Hierarchies that Exclude

Higher education is commonly associated, by the public at large, with notions of freedom—freedom to think, learn, speak, study, and research. Outsiders may expect to encounter, within universities, a relatively liberal, co-operative and enabling structure. It can therefore come as quite a shock, for service users keen to be involved in training, to be faced with what is essentially a hierarchical structure, with a built-in pecking order and ‘institutional’ feel. The notion of expertise is a key one within this culture. There may be resistance to the involvement of service users and, as in practice settings, perceived dangers for lecturers and tutors in letting go a little of the ‘expert’ role. Professions, too, have their specific curricula and may be bound by the requirements of professional bodies. Service user voices have often been excluded from these in the past.

You can GET ROUND THIS BARRIER by preparing newcomers carefully for the world they are about to enter and providing them with opportunities to speak with others who have made the journey recently. This may involve lecturers in getting in touch with how they themselves experience their own institution, evaluating the constraints that this may place on them, and considering how they will respond to these. One way of combating the arguments of those who place a premium on ‘expertise’ is with a ‘top-down/bottom-up’ approach—harnessing, on the one hand, the weight of government policies that champion the importance of drawing on ‘experts by experience’ and, on the other, the views of students who often evaluate the involvement of service users highly.

## 2. Stigma and Discrimination—Not a Service User-Friendly Atmosphere

Universities, although places of great knowledge and resources, are by no means free from the forces of discrimination. Service users may be seen as ill (all the time), unreliable or even dangerous. This may be reinforced—within individual disciplines—by a predominantly medical/biological model of mental health. These pressures, which may act directly to exclude service users from involvement in learning and teaching, may also create for lecturers and students a climate in which disclosure of their own experience of mental ill health can feel dangerous. It can be difficult for those unable to be open about their own experience to pave the way for others to be involved.

Universities do not have a good record with regard to looking after the mental health of staff and students. This is a big issue that is just emerging. As universities seek to involve more service users in their mental health training and education, what support do they give to their own staff and students who have mental health problems? How easy is it for a mental health lecturer to speak out about their own mental health difficulties? This is not just an issue for education. The publication *Stronger than Ever—A Report on the First National Conference of Survivor Workers* (Snow, 2002) may help in overcoming barriers in this area. Service user-involvement initiatives may be more likely to come from junior/part-time staff and those with the

greatest connection to practice—they may face a lot of the same issues, dealing with university jargon, complex systems, bureaucracy and lack of support.

You can GET ROUND THIS BARRIER by emphasising the strengths of service users, their abilities to obtain qualifications and hold down jobs. People have also addressed this by identifying and bolstering their own sources of support. At an institutional level, developments such as the Health Promoting Universities initiative (Dooris, 1999), provide a mechanism for addressing issues of discrimination at all levels.

### **3. Validation and Accreditation Processes**

These processes usually involve a series of meetings, with many people in attendance (they are the academic equivalent of the ward round or CPA review meeting). These can be experienced, especially by those new to them, as a form of ritual initiation; characterised by obfuscation, ‘point scoring’, and bullying. Where service users and carers are involved in such processes they often feel disempowered and, bamboozled by acronyms and jargon, effectively silenced. Although universities increasingly like to have a ‘user rep’ at the meetings, unless well thought out this can be experienced as tokenistic—mirroring a growing sense, from service users across the breadth of mental health services, that being an isolated ‘user rep’ within a committee structure may not be the best way to have an impact.

You can GET ROUND THIS BARRIER by working together to make the process more humane; only involving service users in it if they have a real desire to be part of it and a genuine role to play. It should be noted that it is not only user representatives who can find such meetings difficult. Whether junior or part-time teaching staff, practitioner and student representatives are involved may have a bearing on how these meetings and structures operate.

### **4. Academic Jargon and ‘Put-downs’**

As in all fields, the academic world has its own jargon. Sometimes this is worse than in other fields, as an aspect of the job of an academic is concerned with clear definition of specific terms and descriptions. Academics have been known to go into great detail about the difference between terms like ‘interdisciplinary’, ‘intradisciplinary’ and ‘multidisciplinary’ or to debate for hours the difference between a ‘reflective’ and a ‘reflexive’ practitioner! This sort of approach can be distancing to those involved (service users or workers) on the front line of mental health services.

Academic put-downs are hard to handle as they can make you feel that you are basically stupid. For those who have attended or worked in universities at previous stages in their life, this can feed too on prior negative experiences.

You can GET ROUND THIS BARRIER by establishing ground-rules that encourage the asking of questions (however seemingly simple) and permit and encourage the challenging of all jargon. You can also create opportunities for people to share how they are feeling—it can be helpful to service users to know how

disempowered and insecure about their own ‘cleverness’ some people who work full-time within universities can feel.

### 5. Clever People/Clever Excuses

We are all used to the many excuses for not involving service users. Crepaz-Keay and others (1997) listed a number of excuses such as ‘they’re not ready for it’ and ‘they are not representative/not like our clients’. People who work in universities, being (if not always feeling!) on the whole quite clever, can come up with well-argued excuses, drawing on established ‘evidence’. Recently we have noticed a tendency to consult endlessly before taking action.

Anne Beales, when she was working as Director of CAPITAL (Clients and Professionals in Teaching and Learning) in 2004, told us of her experience of this:

The commonest form of resistance to our inclusion in the academic world is a form of ‘never-ending consultation’. For some five years CAPITAL has worked with a number of universities in teaching, running workshops and groups. In 2003, we were commissioned, and delivered a report around service user inclusion/involvement in education based on focus groups, which looked at all the key issues. The focus groups were with people who had a variety of physical disabilities and sensory impairments, people who were homeless, parents of children with disabilities and people who were mental health service users who were not members of CAPITAL. The report was acknowledged as ‘excellent’. Yet, in 2004, can we look forward to discussions with commissioners of training and education, design of course programmes by the course boards, selection and appointment of lecturers, agreed payment for consistent participation in education including marking of assignments? Can we look forward to an agreement around ethical practice, ensuring safety for those who participate and an outcome of learning by all? Nope, you’ve guessed it, we’ve been asked back for more consultation on the issues.

You can GET ROUND THIS BARRIER by *just doing it*—the excuses soon fall away as the working relationships develop. It may be useful to get lecturers thinking about how they counter opposition from more senior or influential colleagues. Positive feedback from students, as ‘consumers’, can be extremely powerful here—as ‘customer satisfaction’ holds increasing sway in universities. Also, increasingly, commissioning bodies will be insisting on service user involvement in all programmes. See, for example, the *National Continuous Quality Improvement Tool for Mental Health Education* (Northern Centre for Mental Health, 2003).

### 6. Knowledge as King and Topics/Levels

Sometimes the academic world, with its emphasis on knowledge and ‘aiming for the head’, can fail to balance this with the passion of education ‘aiming for the heart’. Most of the key messages from service user/survivor trainers have their roots in a shared sense of personal experience and a related passion for change that can sit uneasily within the world of higher education.

A lot of teaching in higher education is also related to specific topics. Traditionally this translates as ‘what the lecturer knows about the topic and what level they can teach it at’. Teaching is often seen as lecturing. Also, the emphasis within universities on research can leave little time for planning teaching in general, let alone working out objectives with service users involved, resulting in a ‘Just wheel ‘em on’ approach that service user trainers generally do not find helpful.

You can GET ROUND THIS BARRIER by first acquiring and then making full use of the growing service user/survivor literature and, backed up by recent policy documents, emphasising the importance of values and attitudes in training and education.

Another approach is to take a broader view of learning and teaching. Service user/survivor trainers, working with colleagues in higher education, are now involved in course design and planning—sometimes developing and running whole modules, assessment and evaluation—as well as in practice learning. Sessions are delivered on legislation, policy, approaches, treatments, advocacy, self-help and self-management as well as inputs based on personal experience and personal stories. Service user/survivor trainers will often feel quite comfortable in moving away from the traditional ‘chalk and talk’ approach towards creative teaching methods in their work. Increasingly, universities are placing an emphasis on innovative learning and teaching—backed up with development funding which lecturers can use to buy themselves out of teaching. This can be accessed to get around the time constraints. It can also be helpful if user involvement is part of a spectrum of input, which also draws on the experience, and perspective of practitioners and carers.

## **7. Individual and Not Team Approach**

The ethos within higher education can feel very individualistic, without much of a sense of team working, and with few initiatives that cross boundaries between the training of different mental health professionals. This can cause difficulties for service users who have input into different parts of programmes, or across several departments or schools. It can be difficult for people who come into a course for specific inputs to ascertain how these fit within the whole course.

You can GET ROUND THIS BARRIER through developing ‘shared learning’ initiatives that cut across schools and departments. Universities have also got around it by appointing service user and carer development workers at school or faculty level with a role in providing co-ordination and support.

## **8. Gaining Access in the First Place**

People who work in higher education may not know how to access service users and carers who might want to be involved. They may be unsure whom to approach. There is a temptation to get one or two people involved and then to leave it at that. This can lead to worries about tokenism, as well as to the over-use of a few people. Similarly, service users who want to become involved may not know whom to contact at a

university. This has become less of an issue as service user groups have become more established and education and training partnerships have begun to be set up.

You can GET ROUND THIS BARRIER by using networking skills, working out what supports are available in advance and by considering it important to develop and nurture a strong relationship between service user/survivor trainers and their organisations. Knowledge of 'local politics' within community networks can be important here.

## **9. Bureaucratic Payment Systems**

Barriers and delays associated with payment can be very disheartening for service user/survivor trainers and their organisations. Universities often have rigorous, and quite inflexible, payment systems. Service user/survivor trainers are involved in only a minority of departments and resolving systems for their payment can be low on the list of priorities.

As an example, we read with interest (on the Mental Health Foundation's 1 in 4 forum) the story of a service user trainer who had asked for 80 pence to be refunded by a university for her bus fare to a teaching session. There was no petty cash available and so she was asked to fill in a form. A month later she received a cheque from the University for 80p!

You can GET ROUND THIS BARRIER by careful preparatory work with the finance department. This is rather tedious, but very important work. It involves mental health awareness training and may sit well as part of a broader 'health promoting university' initiative. Making contact with colleagues involved in mental health teaching in other disciplines/schools, sharing practice and dilemmas and making joint approaches to university authorities can be invaluable.

## **10. Lack of Support for Trainers/Educators**

All trainers/educators need feedback on their input, a chance to debrief and an overall sense of being held within a network of support. Involvement in higher education institutions can be quite frightening, as you may find yourself in a room confronted with 60 students or more. If you don't know in advance how many students you will be speaking to, the layout of the room, the resources and equipment available, and where the students are coming from—both literally (what session preceded yours?) and metaphorically (what disciplines are they from? What is their make-up in terms of age, cultural background, gender etc?)—then the experience is likely to be daunting. In addition service users may feel vulnerable in training roles, as they are often drawing on their own and other people's difficult and traumatic experiences. They may also feel under pressure to perform consistently at the highest level, in order to silence doubts about their involvement. Support is crucial but not always there.

You can GET ROUND THIS BARRIER by making sure that support is a crucial part of any contract with service user/survivor trainers. Firstly, it is very helpful if you

are able to give service user/survivor trainers a clear brief. The basics around welcoming trainers and making sure they have the right equipment (that works) are also important. Access to library and IT resources can be a great help. Enabling service user/survivor trainers to work in pairs can be helpful. It is important to ask service users about their own support strategies, which may be quite sophisticated.

## Conclusion

Service user and carer involvement in education is key to the development of sensitive and effective practitioners able to deliver the kinds of services that people need and want. Achieving a greater influence in higher education is an important goal for service user/survivor trainers, as it is within higher education where most mental health training is delivered. Much progress has been made, as a recent good practice guide *Learning from Experience* (Tew *et al.*, 2004) reveals, but there is a long road still to travel. Progress can only be made by service user and survivor trainers working in partnership with colleagues in higher education. If those colleagues were enabled to speak more openly about their own experience of mental distress, that could be very powerful.

We have in this article drawn on our own experience, and that of others, to suggest ways—some simple and others more complex—in which a number of common barriers to involvement in higher education can be overcome. This is not to underestimate the task that lies ahead of all of us. Whatever your role in mental health education, you will need to think about how you can draw on experience and seek to avoid reinvention of the wheel. Who might support you in your endeavours? We have focused here on the academic context, and the particular challenges that it can present. It does, of course, in many aspects mirror other settings. In building your own strategy for overcoming the barriers you face, try to think beyond the boundaries of your own discipline and context. What resources—both local and national—might you draw upon? How can you seek to share your own experience with others?

We would advocate a holistic approach to involving service user/survivor trainers. We believe that education is ‘for the heart’ as well as ‘for the head’. We hope that all involved in higher education:

- think it is essential to incorporate the service user perspective;
- feel and believe this is the right thing to do; and most importantly of all,
- do it.

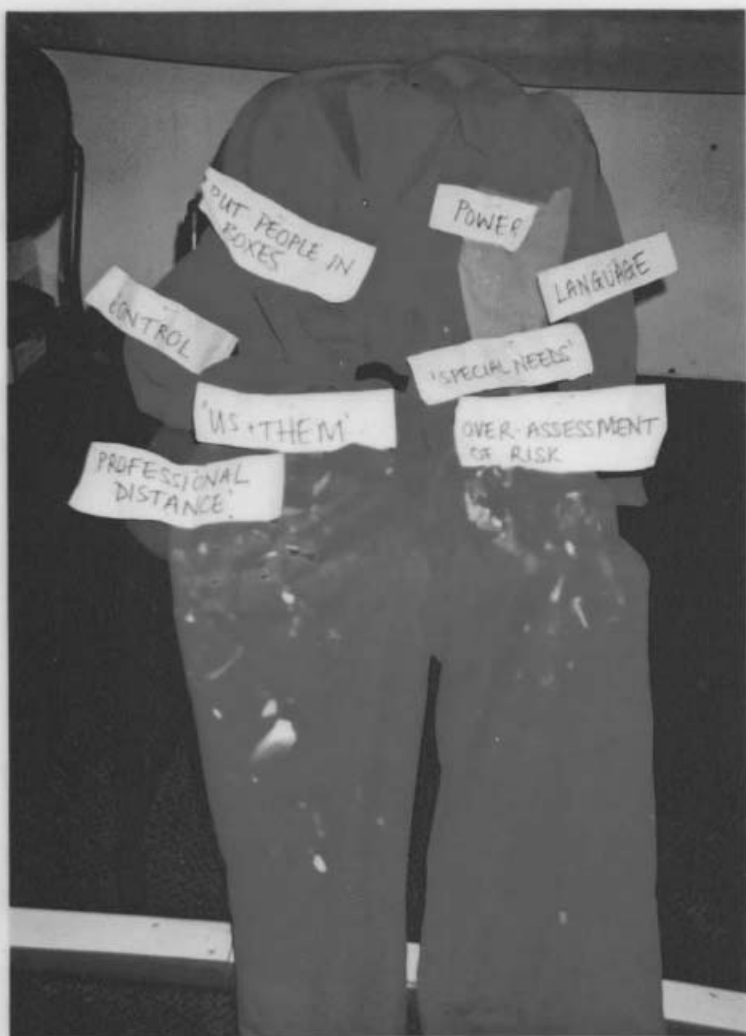
## Note

- [1] Further information about the project, along with a downloadable version of the good practice guide can be found at [www.mhhe.heacademy.ac.uk](http://www.mhhe.heacademy.ac.uk).



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**protective clothing for social workers**  
(to minimise risks of contact with service-users)

ADVOCACY IN ACTION 'CHALLENGING BEHAVIOUR ROAD-SHOW' 2004

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