Design, delivery and evaluation of teaching by service users and carers

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Abstract

Education influences individual health and social care professionals and the system in which they work. We describe a post-graduate educational programme which did this through involving service users and carers in designing and facilitating teaching programmes.

A module of teaching was designed and delivered in partnership with users and carers from older people's mental health services to a multi-disciplinary student group. Its evaluation employed written feedback and separate focus groups involving students and service user/ carer teachers. Both groups highlighted the profound effect of the teaching, and the involvement of users and carers was a powerful experience for all involved.

Background

Education is one way to influence the health and social care system. Tew, Gell & Foster (2004) have argued that the involvement of service users and carers in education at all levels is essential if health and social care services are to develop partnership working with people using their services. They describe how this may involve service users and carers in a broad range of activities, including: programme management, recruitment and selection of students, course and module planning, the direct delivery of learning and teaching, practice learning, student assessment, and course evaluation. Involving service users and carers at all levels of education sends a powerful message to the professionals they train about the value and importance of hearing and respecting the voices of those using their services.

This approach fits with current policy in the United Kingdom (Department of Health, 2000; Department of Health, 2002; Department of Health, 2005; Department of Health, 2006; House of Commons Health Committee, 2007).

We describe in this paper an initiative at the Centre for Ageing and Mental Health, Staffordshire University, to design, deliver and evaluate a module of teaching (In our Shoes) on service user and carer experience aimed at a wide range of professionals working in health, social care and other related services for older people with mental health problems (including housing and chaplaincy). This was achieved through partnership with service users and carers from older people's mental health services. We succeeded in obtaining a mini-project grant from the Higher Education Academy to support travel and other costs of those involved.

Methods

Initially we set up a small curriculum group which included a service user, a carer and representatives of third sector organisations. The group developed overall learning outcomes (Table 1). After discussion we organised focus groups ('design focus groups') to consider the content of the course. From the focus group themes the curriculum group developed a 13 week module plan (see Table 2). We also organised a training workshop for users and carers who were potentially interested in teaching, and asked people to volunteer to teach sessions they were interested in. A service user member of the group gave a presentation at the workshop on her experience of teaching and from her comments we produced Kath's top ten tips for users and carers (Table 3). During delivery of the module, students and service user/ carer teachers were given feedback forms to complete anonymously after each teaching session and, after completion of the teaching programme, each group (ie students and user/ carer teachers) was invited to a focus group ('evaluation focus groups'). All those involved gave informed consent to take part in the evaluation.

All focus groups were recorded, transcribed and subjected to thematic analysis (Boyatzis, 1998).

Findings

Design focus groups

Key words and key themes from the design focus groups are set out in Table 4. Thus themes from the focus groups developed into topics for the weekly sessions as set out in the module plan (Table 2), and users and carers would talk about their personal experiences as far as they wished to illustrate the selected theme. We also included a requirement for students to interview users and carers in their own work

settings (with their informed consent) at intervals throughout the course and feed back their learning from these interviews (see column of Table 1 headed preparation).

Student evaluation focus groups

Table 5 sets out the key words and key themes from the student evaluation focus groups. The students were very positive about involving service users and carers in teaching and about the module as a whole. They felt that it made them see things from a different point of view and that they had learned a lot from the sessions. They acknowledged the importance of taking themselves and the service user/carer teachers away from their usual environments and roles.

Suggestions for potential future developments to the course included the following: using multimedia presentations, including professionals from both health and social care alongside service users and carers to get additional perspectives; looking at a pathway/ theme e.g. "follow a person" through their service experience, or similarly inviting a family in and tracking their experience through the service; including sessions from voluntary organisations or service user/ carer organisations; including people in care homes. Students felt that the option of engaging in questions and discussion with both users and carers was particularly valuable. Employing a variety of teaching methods was seen as strength, but the students' preferred option was the direct personal contact of having service users and/ or carers in the classroom as teachers.

Service user/ carer evaluation focus groups

Similarly the service user and carer teachers were positive about their experience of teaching. Suggestions for the future included: preparing an outline of questions that the students want to ask in advance to help in preparation; targeting a range of people who come into contact with older people with dementia or other mental illness as potential course participants eg police officers /educators. In one session two carers and the two spouses they cared for talked with the students together as a group: in retrospect the carers suggested meeting the students separately from the two service users in order to give everyone chance to speak freely. At the beginning of most sessions students presented brief interviews with service users/ carers in their own practice: usually service users and carers weren't present for this although that had been the original intention, and the group felt this might be something to develop in future.

Tips for service users and carers thinking about teaching included: observing sessions beforehand to help with preparation and cut down anxiety; preparing people for the setting, eg 'when I came in I thought it was far more relaxing than I expected so I do think that would be worth saying', 'it was a surprise to find it was a nice semi circle sort of thing you are a lot more relaxed about that'; stressing to service users/ carers that everyone is different, everyone's story is different: 'what they need to know is they just need to tell their story and not worry about getting it right or wrong'; although it may be difficult to share distressing issues it helps eg 'if you gloss over it they are not getting the real picture of what it is like to be a carer, or the situation'; also it is important for students to see that different people react/cope differently.

Tips for professionals on including service users and carers in teaching included: 'don't call it teaching' instead call it - come and share your experience or your story/ your life; focus the topic of the talk to make it easier; information given to service users needs to be simple and basic – avoid too much information as it might make people anxious; be flexible in approach, accommodate individual service users and carers to get maximum potential; give students the chance to ask questions that they wouldn't have the opportunity to otherwise in their everyday work; there are taboo things in relation to dementia/mental illness which need to be addressed and shared rather than avoided; some service users/ carers feel better talking one-to-one – some people might prefer to make a video rather than meet up with a group. The service users/ carers felt strongly that video teaching does not have the same impact as someone teaching in person: students can't ask questions and lose the interaction.

Teachers also stressed that that if what they say makes a difference then 'it's worth it', and expressed the view that one aim was to improve services for other people in similar situations. They also believed that real-life experiences show students that everyone/every situation is different and make things more 'real'/ impactful. The perceived impact on service user/ carer teachers is illustrated by the following quotations from carers:

> 'I am there on the front line doing it and I found it was good therapy for me to be able to come out of that situation and then put it to people who have not

got the illness and talk with people on a different level, do you know what I mean, I just feel that I found it was good for me.'

'I felt that I had helped, you know, my biggest thing is because of my experience with like Social Services I thought I am talking to people there who are going to go out in the future perhaps us just telling our little bit it helps a little bit and I think it did to a young gentleman who was sitting with us. I think he is a Social Worker and he was quite shocked at a number of things that we said. I thought if you are shocked enough about it then perhaps you will go out and try to do it his way - so for me I think it was the fact that I perhaps could have helped to get somebody to go out and think a bit different.'

'I must admit my grandson did a double take when I told him I was going over to Staffordshire University. What are you going there for Nan? I am just going to help these students.'

Discussion and reflections on the processes involved

The HEA project was completed successfully (Benbow & Boyce, 2008) and the project met its intended aims. The use of focus groups allowed for detailed evaluation of the module and generated a range of helpful suggestions in terms of the future of the teaching itself and practical tips for the future, highlighting the importance of building robust evaluation into teaching programmes The distinctive feature of this module was the embedding of relational aspects of teaching into the design, delivery and evaluation of the module. In the classroom the service user/

carer teachers interacted with a tutor, who had worked with them before the session and during it, in delivering a topic which has been identified in relationship with service users and carers. Both service users and carers as teachers interacted with the students. All parties brought into the learning environment their own experiences, skills and knowledge. The teaching itself established a relational interaction which potentially changed/ evolved or modified the ideas of all those involved. Knowledge is not an entity imparted in a vacuum: inevitably knowledge is created in the social interaction or relationship of all those involved (McNamee, 2007).

The way that students' ideas/ beliefs/ experiences develop outside the classroom throughout the period of the course adds further complexity. The tutor, service user/carer-teachers and students cannot experience the teaching 'in a box' separate from their ongoing life as professionals, family members and people with a multiplicity of roles. The ideas/ beliefs which they take from the classroom go with them into their everyday life and are evolving before they return for the next teaching session. This suggests that if classroom sessions are missed they can never be fully compensated as the richness of the interrelationships that characterise the learning experience is lost, even though the student may develop ideas in internal dialogue.

Service users and carers, who agree to teach, share their stories, views, experiences, and beliefs. The process of doing this is an experience which carries the potential for the service user/carer teachers own beliefs to evolve. A person who is living with dementia may be wrestling with the challenge that it poses to their sense of self and autonomy. Their family may be concerned about the balance between independence and dependence, and the possible need for protection as the

illness progresses. A service user/carer teacher who shares her/his views and experiences in discussion and debate with a group of professionals in health and social care enrolled as students on a higher education course will question their own view of themselves, their family's and society's beliefs about their worth and potential. This is particularly relevant as frequently these individuals are regarded as passive, non productive and in intellectual decline (Withnall, 1995). For this reason respectful recognition of the role that service user/carer teachers play is essential. Many institutions have protocols or procedures for paying visiting lecturer fees, reimbursing expenses and recognising in other ways the important contributions that people make. Utilising service users and carers as facilitators of postgraduate education therefore challenges ageist stereotypes and serves to enrich the lives of these people (Aldridge & Tuckett, 2007).

Thus the experience of teaching is subversive, it carries the potential to subvert attitudes and beliefs that service user/carer teachers hold about themselves and that others hold about them. How will their family members react when told that their relative with a dementia has been a visiting lecturer on a higher education course, what will this mean for their beliefs about that person, their illness, their role in the family and their value in society? Some of the comments made during the evaluation process highlight this.

Tutors who are involved in teaching alongside service user/carer teachers may find the experience potentially powerful. A teacher who has been trained to teach and has experience and background in education may find that their teaching pales beside the contribution of a service user or carer who can bring their experience

uniquely and powerfully to life. The expertise of the tutor is valuable in supporting the service user/carer teachers, in dealing with any practical issues eg travel, expenses, in helping them prepare for the teaching and deliver it in the way they choose in a safe and respectful environment. The tutor will recognise and respect the expertise of the service user/carer teachers in living with and sharing their experiences and beliefs. This relationship and experience may lead to a re-evaluation of the tutor's role and of both the nature of teaching and the design and content of courses. This experience can itself be subversive for the tutor.

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Table 1: Learning outcomes for the course

	By the end of the course students should:
1	Understand some of what it is like to live with a mental health problem in later life
2	Understand some of what it is like to be a carer of an older adult with a mental health problem in late life
3	Have re-evaluated the relationship between health and social care professionals and the users and carers they work with
4	Have re-evaluated what health and social care professionals have to offer in their relationship with users and carers
5	Have experienced learning from the people they work with in their professional capacity

Table 2: module plan

Week	Topic	Learning objectives	Preparation for next week
1	Introduction to the module. Relationships between users, carers & professionals	• To reflect on the relationships between users, carers and health & social care professionals • To consider what is known about what influences the relationship & implications for practice	Students interview briefly one of their clients about their experience of relationships with health & social care professionals (week 1 interviews).
2	Communication: the importance of listening and talking	• To reflect critically on the interaction between users/ carers & health and social care professionals • To reflect on what is known about ways to ensure that users/ carers can express their feelings/ needs/ desires to professionals • To consider how professionals can improve their skills in listening to & understanding users & carers	Students to interview a user or carer or user and carer dyad about their experience of care and how person centred it has been (week 2 interviews). Does the user feel that they have been treated as an individual and that their carer has been too? Does the carer feel that they have been understood and treated as an individual as well as their relative?
3	People not patients 1: getting to know the person	• To critically examine professionals' interactions with users/ carers in relation to whether or not they are person-centred • To reflect on different ways of being more person-centred	Choose one or two items from the reading list, read them through and spend time reflecting on them and your learning so far. Make notes on your thoughts and how useful the items are.
4	People not patients 2: tailoring care/ services to the individual	• To reflect on how person centred current practice is and ways of making practice more person-centred	Students to interview a user/ carer or user/ carer dyad about how far they feel professionals understand their difficulties and feelings

			(week 4 interviews).
5	People not patients 3: acknowledging the experiences & needs of carers	• To reflect on the role of the carer when professionals have contact with users and how far their own needs are acknowledged and reflected in care plans	Choose one or two items from the reading list, read them through and spend time reflecting on them and your learning so far. Make notes on your thoughts and how useful the items are.
6	Choice: being realistic about choices when resources are finite	• To consider whether users/ carers are currently given choice in their interactions with health & social carer professionals • To reflect on what choice might mean for users and carers and how practice might change as a result	Students to interview (week 6 interview) a user/ carer or user/carer dyad about their journey: in what ways have they experienced continuity of care and what ways do they feel care has been fragmented and discontinuous. How would they like to see things change?
7	What is important to users & carers?	• To consider during an interaction between a user, carer and professional what is important to each and how they influence the outcome of the contact • To reflect on ways to make the users and carers wishes more powerful in the system	Choose one or two items from the reading list, read them through and spend time reflecting on them and your learning so far. Make notes on your thoughts and how useful the items are.
8	Continuity of care: the 1:1 relationship & time	• To reflect on the patient journey and the importance of continuity of care to users/ carers • To consider the advantages and disadvantages of continuity of care for all parties involved • To consider how the 1:1 relationship between professional and user/ carer	Students to reflect on what they wish to do differently in future and how they would like their service to change in order to address the needs of users and carers.

		• fits into the complexities of modern health & social care	
9	The role of the environment	• To consider the role of the environment in how a user/ carer presents themselves to professionals • To reflect on ways of understanding the changes that people exhibit in different environments • To consider what this means for professionals in their contacts with users/ carers	Students to interview a family who have had contact with their service about how far they feel they have all been able to be involved & have their needs/ wishes/ anxieties addressed (week 9 interview). How do they feel professionals could do this better?
10	How to work with differing perspectives	• To consider how to acknowledge & take account of the differing perspectives of those involved when working with service users • To reflect on how practice might need to change as a result	Choose one or two items from the reading list, read them through and spend time reflecting on them and your learning so far. Make notes on your thoughts and how useful the items are.
11		• READING WEEK	
12	Sharing experiences: learning from each other	• To reflect on every contact between professional and users/ carers as a learning experience • To consider how learning can be maximised for all parties involved and how this might impact on professionals' future practice	Look through your notes on the reading list items you have read and bring them along next week to the feedback session.
13	Looking backwards to look forwards	• Review and reflection on the module • To consider ways to put learning into practice and how to continue learning into the future	

Table 3: Kath's Ten Top Teaching Tips for Users and Carers

	Ten Top Teaching Tips for Users and Carers
1	Talk about your own experiences, fears and disappointments with the system.
2	Approach it as if you are telling friends that you haven't met for some time.
3	It can help to ask the students to send you the questions they would like you to answer in advance.
4	Don't be afraid to ask the organiser what is wanted.
5	Leave yourself time to get your thoughts together before the teaching.
6	Be yourself.
7	Prepare your talk in advance.
8	Read it over and over again until you are familiar with what you want to say and can talk it rather than reading it.
9	When you do the talk, sit down if you want so the students won't see your knees knocking or hands shaking.
10	Remember, the students want to hear what you have to say. Good luck.

Table 4: Design focus groups – key themes

Service users – key themes	Carers – key themes
Communication • Difficult communication between users, family carers and professionals. • Listen to users and work with them. • Feel a lack of understanding from others. *Knowledge & understanding* • Unless professionals are experienced, users feel that they cannot understand them properly. *Practical issues* • Visiting groups could benefit both carers and users • There is a need for discussion groups as sharing experiences can be important/ beneficial for all. *Person – centred care* • There is a variation in the effects of the illness but users feel like this is sometimes overlooked/ ignored by carers/professionals. • Users, immediate carers and professionals are believed to have different views/perspectives.	*Communication* • Communications between professional and family carers are important for both • Feel they are not believed/listened to by professionals *Knowledge & understanding* • Professionals need knowledge regarding the illness • Perceived lack of understanding on the part of professionals *Practical issues* • Carers groups are helpful and might contribute to teaching • Not all users are elderly *Person – centred care* • Every case is different *Carers emotions/ needs* • Confusion/worry/isolation • Frustration • Guilt • Blame *Hidden issues* • Violence from users

Table 5: evaluation focus groups – key themes

Students – key themes	*Teachers – key themes*
• Allows reflection • Opportunity to listen • 'True to life' • No right or wrong • Relationships between academics, health and social care professionals and others • Changes the way you think • Makes us think about our own practice • Share what you have learnt • Breaking down barriers between different groups of people • Working with people more broadly • Users and carers points of view and relationships • Make a difference and improvement • Mixture of experiences • Learning from a unique point of view • Care has changed but still needs to improve • Changing attitudes • Theory and practice • Understanding/seeing the experience of dementia first hand • Balance between carers and users	• Some get upset when they cannot remember things • No right or wrong answers – just real day-today life • People take away what they want to • Distressing/anxiety provoking questions • Enjoyed doing it/ sharing experience • Positive experience • Personal touch • Oppose distance learning • People's perceptions