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Experiences of service user and carer participation in health care education

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Summary The agenda of involving service users and their carers more meaningfully in the development, delivery and evaluation of professional education in health is gaining in importance. The paper reports on a symposium³ which presented three diverse initiatives, established within a school of nursing and midwifery in the United Kingdom. These represent different approaches and attempts to engage service users and in some instances carers more fully in professional education aimed at developing mental health practitioners. Each is presented as achieving movement on a continuum of participation from service users as passive recipients to service users as collaborators and co-researchers.

The paper concludes with a discussion of the lessons to be learnt which will hopefully stimulate service user involvement on a wider basis.

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³ The symposium was prepared by a team of nurse educators, service users and researchers from the UK and an academic from Australia.

Introduction and background

Service user (a term inclusive of consumers, clients, patients and carers for the purposes of this paper) involvement is defined as an active and equitable collaboration between professionals and service users concerning the planning, implementation and evaluation of services and education. Implicit in this definition is the transfer of power or control over aspects of service delivery from professionals to service users (Wright and Rowe, 2005).

Government directives in the United Kingdom (Department of Health, 2000), and internationally (Church, 1997; National Mental Health Strategy, 1997), advocate the involvement of service users in health service provision and the education of health professionals. However, it would appear that this drive for service user involvement is mainly emanating from policy directives and users themselves who have campaigned for a voice in health services and education. Widespread professional commitment to the fundamental philosophical need for user involvement initiatives is not apparent (Felton and Stickley, 2004; Summers, 2003). Moreover, while service user involvement in the planning, delivery and evaluation of services has increased over recent years, research indicates that there is a disparity between the philosophy of service user involvement and the pragmatics of practice. Despite an espoused commitment to service user participation, users still express the view that they are not listened to (Chamberlin, 2004; Rose, 2001; Canales, 2000). In an analysis of the UK Commission for Health Improvement's (CHI) first 175 clinical governance reviews, one of the main findings was that few service providers are routinely involving users and carers in the development of services and policies (CHI, 2002).

A number of reasons for including service users in health services and education have been cited in the literature which relate to demands from consumers themselves (Hickey and Kipping, 1998) to increase the power, control and influence of service users (Rose, 2001); to challenge entrenched perceptions and attitudes of health professionals (Katan and Prager, 1986); to break down the barriers of hierarchical and paternalistic services and improve clinical standards and service delivery (Happell and Roper, 2002). More controversially, some have promoted it as a form of therapy - to increase users self esteem and confidence as the roles of 'helper' and 'helped' are reversed (Hanson and Mitchell, 2001). However, Coldham (2003) argues that this is empowerment of service users rather than therapy.

The cited potential barriers to service user involvement include the perception of service user involvement as threatening to staff and their sense of professional autonomy (Katan and Prager, 1986). There is concern that the stress of involvement may damage users' health (Simpson and House, 2003). Service users themselves may be reluctant or lack interest with factors such as age, gender, cultural background, diagnosis, previous health care experiences, personality characteristics and educational background playing a part (Hickey and Kipping, 1998). Not adequately remunerating service users for their contributions can be viewed as exploitative (University of Central Lancashire, 2004). However, until user involvement is viewed as an essential part of service provision or education it is recognised that resources are limited.

Involvement of service users in professional education

The primary reason for involving service users in the training and education of mental health professionals is the anticipation that it will produce practitioners capable of delivering improved and more relevant outcomes for users and their carers (Tew et al., 2004). Furthermore, underlying the policy statements of service user involvement in education is the growing expectation that the health services should involve service users to a greater extent in decision making (Felton and Stickley, 2004). Therefore, health professionals need to be adequately prepared during their education for the increased involvement of service users in both personal care and strategic service decisions (Ikkos, 2003).

The value of involving users in the education of health and social care professionals has been emphasised in a number of reports (e.g. Levin, 2004; Holsgrove, 2005; Department of Health, 2006) and there is some evidence that users are being included in the curriculum planning and development of nursing programmes, classroom work and clinical assessment of students (e.g. Khoo et al., 2004; Morgan and Sanggaran, 1997). While there are some studies that evaluate professional and service user perspectives and attitudes towards involvement (e.g. Forrest et al., 2000; Happell et al., 2002), there are a limited number that evaluate the outcomes of service user involvement on student learning and their subsequent care delivery (Happell et al., 2003; Wood and Wilson-Barnett, 1999), nor allow the service users involved to reflect on their experiences in the process. Fur-

thermore, there are few studies that provide practical advice on how service users can be involved. Much of the evidence is in the form of reports about particular initiatives (Tew et al., 2004).

One school of nursing in the UK has taken steps to promote greater service user and carer involvement in order to further develop the mental health education. This includes three initiatives in particular. The first focuses on the work of a service user and carer reference group. The second is the establishment of a service user academic post and its evaluation and the third is a co-operative inquiry which sought to engage service users in the clinical decisions of mental health student nurses.

The continuum of participation

The advent of consumerism has increasingly meant that clients are invited to participate in consultations about service provision, but this has been largely a passive or reactive process, with service providers retaining control of the agenda. Additionally, until recently (see UK Mental Health Research Network: <http://www.mhrn.info/dnn/ServiceUserInvolvement/tabid/98/Default.aspx>) service user involvement in research has been mainly as subjects, again a passive position that means that their voice is largely absent from the conduct of research and the shaping of research agendas.

A linking feature of three initiatives reported here was the concept of movement across a continuum of participation. This concept has similarities with Arnstein's (1969) well known 'Ladder of Participation', but works in a horizontal plane, as illustrated in Fig. 1. The desire within all of the projects which form the focus of this paper was the creation of a shift from the right-hand side of the continuum, where service users are passive recipients, to the left-hand side, which promotes initiatives or research that are led by service users.

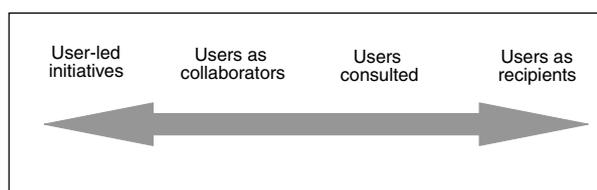


Figure 1 Continuum of participation (services and education).

The service user and carer reference group

A strategy has been developed which adopts an external user and carer reference group (user group). The approach has been informed by other theoretical work such as Abuel-Ealeh and Jarvis (2000) which illustrates successful development of user involvement in another UK University. The user group has been in existence for over 5 years with the aim of sharing a range of views and knowledge of mental health matters and providing advice and expertise to others to help guide the university in developing its programmes. It comprises users of services, carers for people who use services, and allies who work across the voluntary and statutory sector. Members of the group negotiated the terms of reference to include the provision of advice on curriculum development, assisting in the planning and delivery of curricula at pre-registration and postgraduate levels, including those aspects specific to user and carer involvement in mental health services.

Outcomes of the groups participative work have included contributions to curricula design, teaching sessions, review of research proposals and importantly the annual undergraduate 'fayre'. This user-led event has been the opportunity for service users and carers, along with academic staff and students, to engage in participatory workshops on a diversity of topics such as substance misuse, ethnicity and employment. The feedback, especially from students, has been highly positive with an appreciation of user and carer perspectives that has been 'enlightening', 'insightful' and 'stimulating'.

There have been challenges such as the need to nurture participation which requires energy, enthusiasm and commitment. There are also the practical matters of time to attend regular meetings and take part in planning and presenting events. Nevertheless the important lessons learnt include the value of having established members with different contributions to make, the necessity for a budget and other resources, although the costs are relatively low, the involvement of students as well as service users and carers, and the recognition that such a vehicle can be viewed as a 'culture carrier'. Culture carrier in this context refers to the shared belief in the value of participation as an essential contributing factor to organisational change toward more user-centred services. As an approach to participation, the user and carer reference group can be viewed as being towards the left-hand side of the continuum, where users

are collaborators in a process rather than passive recipients (see Fig. 1).

Service user academic initiative

The second project has been the establishment of a post referred to as a service user academic (following the example of a 'consumer academic' in Australia, Happell et al., 2002). The aims of this post were to provide meaningful user-led experiences which would increase the impact of user perspectives on students' learning and to do this in an integrated, rather than 'bolt-on', way. The first phase of the post was evaluated using a case study design underpinned by the principle of democratic evaluation, where the knowledge sources of all stakeholder groups are valued equally. The participants involved in interviews and group discussions were the service user academic; 35 students/trainees; six members of the user group; and ten other members of the academic staff. These data were augmented by documentary sources (policy documents and student evaluations).

The post was viewed as having many positive outcomes. For example, it raised the esteem of the academic team (lecturers and students) and was a resource for the academic grouping providing a knowledge source for staff and students and prompting others on the involvement agenda. As one of the lecturers observed:

"[the postholder] would make sure there were user/carer strands through everything. She was good at that because she formed good working relationships with the team so she was able to say "where's the user/carer bit in that then?"

Importantly, the post provided an optimistic model for students:

"[The service user academic] reminds you that there is a different life beyond the illness... It is hard when you are working in an acute ward to keep this in your mind, that people can achieve a great deal. It gives hope as it is easy to become pessimistic and we can take that hope back to the practice setting. Seeing a service user who is also an academic, you realise that anything is possible."

On the other hand, some challenges were identified, for example, the potentially stigmatising nature of the title of the post. As a student said

"I wonder why you actually have to label a service user in the first place... I wonder if it makes them

feel like a second class person?... If you are labelling them are they being treated differently in other ways?"

Furthermore, there were mixed expectations of the role which remained unresolved in practice. The role occupant was expected to take a lead in the involvement agenda which included teaching, curriculum planning, chairing and developing the User Group, but there was space for thinking and creativity. Conversely, they had none of the time consuming responsibilities of a lecturer in terms of leading several learning groups and copious marking of assignments, and as such was identified as "different from lecturers" and not integrated into the overall education delivery. Nevertheless, the evaluation demonstrated that a pioneering post such as this has the potential to fundamentally change the culture of the educational establishment, the nature of the educational experience for students and directly impact upon practice. Similar to the service user and carer group, it demonstrated a move along the continuum to involving a service user as a collaborator in the delivery of mental health professional education (see Fig. 1).

A co-operative inquiry of service user and student participation

This was a study about the participation of mental health service users in the clinical practice decisions of mental health student nurses undertaking their nurse training. There were three key concepts pertaining to the participation literature which had a significant influence on the preparation for this study: anti-oppressive practice; contact theory and moral development. An extensive discussion of these concepts is beyond the scope of this paper. However in summary, anti-oppressive practice focuses on empowering individuals to understand their rights and progress toward effective citizenship. If nurses are to promote participation as a technique for overcoming oppression and responding to the aspirations of service users, then learning needs to focus on developing opportunities in equal partnership. Contact theory postulates that if contact between groups of people increases then this leads to more positive attitudes toward each other. Kohlberg (1984), examining the development of moral thinking, determined that individuals progress through six stages, from seeing morality as external to themselves and punishment toward the development of notions of fairness, goodness and duty and recognition that different social groups have differing values with decisions

being based on equal respect for all. There is a need for the professional provider of care to carefully examine and understand their own value base in order not to prejudice the values of those in receipt of services.

It was the consequence of careful consideration of the implications of each of these concepts which led the researchers to consider an emancipatory research design which both embraced anti-oppressive practice and which facilitated meaningful contact allowing deep learning to take place. The research was undertaken with students, from the school of nursing and midwifery, in collaboration with mental health service users, recruited from mental health service user organisations, and was conducted over a period of 18 months. The inquiry sought to explore how service users could be more effectively engaged in students' clinical decision-making (see Tee, Coldham et al., 2005).

The outcomes of the inquiry have been to identify, from a service user and student perspective, professional values which respect the individuality of the person; behaviours and actions which share power and reflect belief in individual potential; and cultural aspects within organisations which enable shared learning and full participation in decision-making.

The co-operative inquiry seeks to share power in research, and as such is deemed to be more ethical, and less exploitative, than some other designs where participants are viewed as passive subjects (Tee and Lathlean, 2004). The continuum of participation in Fig. 1 can be modified to fit with the research endeavour (see Fig. 2), and in this project, the shift was to involving service users as co-researchers.

Discussion and conclusions

The purpose of each of these projects has been to develop and evaluate different aspects of 'good practice' where participants are able to be active agents of change in processes of research and education 'with', rather than 'on', service users.

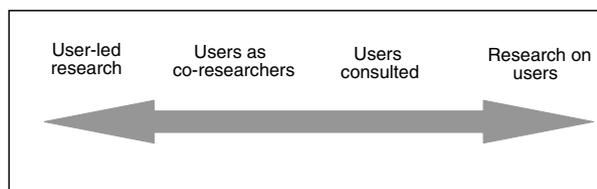


Figure 2 Continuum of participation (research).

Transferring such approaches to the wider education and clinical learning environments requires a move away from clinical and professional paternalism toward greater devolved decision-making. Each project achieved some success towards greater service user participation in the teaching and the learning activities. Integrating the experiences and findings from the three initiatives highlights the need for a range of methods to achieve this across an organisation. However, this integration has also emphasised the common obstacles to such developments.

It was evident to many of the participants (both service users and academics) involved with these projects that achieving a culture of true participation across clinical and higher education providers is something which requires constant vigilance. Everyone has a responsibility, and it cannot be sidelined to the role of one or two individuals. It is a philosophy which needs to pervade all tiers of service and education organisations and all health and social care disciplines. It impacts on everything that is done and should therefore be an early consideration before any decision to act is taken, as illustrated in this recent example of 'care':

"I just wish professionals would listen to me more, even to this day they have their own agenda. Somebody walks through the door and they think they can tell what's wrong in the first ten minutes. I want them to see past the diagnosis"

Many service user participants in these projects shared considerable frustration concerning previous efforts to increase user involvement elsewhere. These had withered due to lack of organisational commitment, individual 'champions' leaving or funding priorities changing. Such tokenism devalues user initiatives and reinforces the 'institutional userism' which leads to exclusion and disempowerment. The experiential knowledge and research findings emerging from these projects reflect a complex mix of attitudinal, skill and service design dimensions which all, arguably, need to be present to enhance user-led decision making in the education and practice environment.

There is the need for more dialogue and debate which this paper intends to stimulate. However, a significant limitation is the lack of rigorous comparative studies which aim to assess the impact of involving service users in the delivery of health professional education. Furthermore, potential or real barriers to service user involvement should be identified and considered with user colleagues, so that where possible barriers can be overcome and unrealistic expectations avoided. Articulating these aspects will help secure the organisational

and resource commitments to promote a culture of true participation.

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