

Mental health service user involvement in nurse education: exploring the issues

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This paper reports on findings and issues arising from a study designed to promote mental health service users' involvement in a preregistration nursing curriculum. Users' views about the knowledge, skills and attributes required by mental health nurses were explored to inform the curriculum design. Strategies that would facilitate long term, active user involvement in the design and delivery of the curriculum were also explored. Findings are presented with concurrent discussion of issues arising from the research process in relation to user involvement in education. The issue of 'conflict' explores findings relating to users' views of a 'good' mental health nurse and inherent conflicts between user and professional views are highlighted. The representativeness of the research participants is explored and debated in relation to service user involvement in nurse education. Finally, the concepts of 'involvement' and 'tokenism' are discussed and recommendations made about how active user involvement in nurse education can be achieved.

Keywords: education, involvement, mental health, preregistration, representativeness, service-user

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Introduction

This paper discusses findings and issues arising from a study that explored ways of involving mental health service users in a preregistration mental health nursing programme. Issues relating to user involvement in nurse education are discussed concurrently with selected research findings.

Service users' views of a 'good' mental health nurse are explored and inherent conflicts between user and professional views highlighted. The issue of the representativeness of research participants is debated in relation to user involvement in nurse education. Finally, the issues of involvement and tokenism are discussed and recommendations made about the way forward for user involvement in education.

Background

The notion of user involvement in nurse education has gained momentum over the past decade (DoH 1994a; ENB 1996; Rudman 1996a). The move towards involvement in education is set in the context of health care policy dominated by consumerist concerns (National Health Services for Scotland 1991; 1993; Brunning *et al.* 1994; DoH 1994b; National Health Services Executive 1996).

The government review of mental health nursing suggested that service users should develop roles in curriculum development and teaching (DoH 1994b). Several other authors note the benefits of involving service users in education (Stevenson & Parsloe 1993; Butterworth & Rushforth 1995; Edwards 1995; Wood & Wilson-Barnett

1999). Students' understanding of individuals' experiences is enhanced, along with a respect for individual differences and a greater understanding of the social context of peoples' problems (Beeforth *et al.* 1990, DoH 1994b; Butterworth & Rushforth 1995; Glazier & May 1995; Rudman 1996a). Importantly, service users can define what they need from mental health services and professionals and share their perspective and experiences of the services they have used (Stevenson & Parsloe 1993; ENB 1996; Rudman 1996b). Educationalists and students can also begin to understand the individual experience of mental distress.

Aims of the study

The research had two aims, firstly, to elicit users' views about the knowledge, skills and attributes they considered mental health nurses should possess. It was intended that the curriculum could then be designed in a way that promoted these desired qualities. Secondly, the research explored strategies whereby users could be involved in ongoing curriculum design and delivery.

Method

The research was qualitative and involved conducting focus groups with mental health service users. The groups were conducted using a semistructured technique incorporating a series of questions initially derived from the research objectives and literature review. Focus groups are described in the literature as a method that lends itself to the exploration of the views people hold about particular issues (Stewart & Shamdasani 1990; Kitinger 1994). Ethical approval for the study was granted by the local Health Board Ethics Committee.

In total 34 people participated in five focus group discussions. The groups comprised a maximum of eight and a minimum of four service users. Participants were recruited with the assistance of advocacy workers and workers at 'drop in' centres and all participants agreed to voluntarily take part in the study. Three of the focus groups were conducted with users affiliated to users' organizations and two with users attending mental health 'drop in' centres.

The collection and analysis of data were concurrent processes. Focus groups were tape recorded and transcribed. Transcripts were scrupulously read and independently coded by all four members of the research team to generate a thematic analysis. The themes generated were constantly revised and categorized as data collection progressed. This approach to data collection and analysis allows for the constant formulation and reformulation of

categories emerging from the data in a way long established in qualitative research and associated with the grounded theory approach (Pollock 1989, Strauss & Corbin 1990, Lofland & Lofland 1995). Fuller details of the data collection process and the methodological issues that confronted the researchers are described in Forrest *et al.* (1998).

Discussion of findings

Four consistent themes emerged from the analysis, however, it is beyond the scope of this paper to explore all findings in detail. Selected findings are presented in a way that enables concurrent discussion of the findings and issues arising from the research process.

The issue of conflict

It has been previously noted that service users' perceptions of their needs and help they would like to receive often differs from professionals' views (Barker 1994, Shepherd *et al.* 1995, Murray 1997). Participants in our study were generally critical of the care they had received from mental health nurses. A 'good' nurse was frequently described by users as someone with the lay qualities of: 'common sense'; 'warmth and sensitivity'; 'being nice', and 'someone who can be a friend'. These findings are consistent with other research which suggests that service users appear to value professionals' interpersonal and 'human' qualities rather than specific therapeutic approaches (McIntyre *et al.* 1989, Ballard & McDowall 1990, Arnold *et al.* 1992, Rogers *et al.* 1993, Lothian Health Council 1996).

Many participants considered that nurse education had a questionable role in promoting the qualities they valued. Rather education was perceived as instilling (as is the intent) professional qualities and knowledge in students. What is notable is that professional qualities were generally not valued by users, and indeed could be viewed as detrimental to nurses' ability to help. Participants' perception of professional qualities was linked to their experience of treatment dominated by the medical model of mental illness, with a focus on diagnosis, symptomatology and medication. Most participants had previously experienced treatment in acute admission wards and described their treatment as comprising drug treatment and observation by nurses. This finding is also consistent with other research that highlights the continuing medical model dominance in psychiatry and its impact on mental health nursing (Whittingham & Parsons 1999).

Many participants suggested that nurses who had been educated and professionalized through the hospital based mental health 'system' ended up perceiving and interacting

with users as 'text book cases', rather than individuals with unique experiences of distress. Professional qualities were also seen as eroding the human qualities they valued and this in turn led to 'distance'. Several authors point out that the use of professional terminology and routine, standardized approaches to care are often the outcomes of professional education and serve as mechanisms of maintaining professional control by distancing (Brandon 1991; Wilkie 1999 and Wood & Wilson-Barnett 1999).

The view that professional education was in some way detrimental to an individual's human and caring qualities was held strongly by several participants. As one person stated:

'The most important thing nurses can do is abandon their training'.

These are uncomfortable views for educationalists to hear and obviously conflict with many of the values underpinning nurse education. However, findings suggested that the conflict between human and professional qualities is of crucial importance. Perhaps the most helpful way to view this is not in terms of a dichotomy, but as a continuum with 'human' qualities at one end and 'professional' qualities at the other. Human qualities refer to a nurse's ability to be a 'friend' to users by acting in a sociable and human way. Professional qualities relate to 'professional' knowledge and skills that result from a formal education. Nurses are able to possess both human and professional qualities concurrently. However, the key appears to be that if a nurse cannot function at the 'human' end of the continuum there cannot be progress towards professional help.

Nurses may also need to find the right balance, and be able to recognize the person's needs at any one time and slide up and down the 'human' 'professional' continuum accordingly. Our findings reflect the need for mental health nurses to progress to a new type of caring, described by Barker & Whitehill (1997) as 'caring with' rather than 'caring for' people. 'Caring with' people implies a partnership, shared responsibility in the caring process, and an equal relationship. 'Caring with' may have its starting point in nurses' human qualities and nurses' ability to focus on and understand the human experience of distress (Barker 1996).

Our findings strongly suggested that being able to function as a friendly human being was seen by service users as key therefore the curriculum should aspire to promote and protect these qualities in students. One way that may progress this is by ensuring that the curriculum emphasizes self awareness, interpersonal skills development and a focus on people rather than diagnosis. Barker *et al.* (1997) suggest that for effective relationships to be established respect for the unique experience of the person must be expressed. Emphasis must be placed on learning *with*

service users, not just learning *about* professional stereotypes of mental distress. There is some promising research demonstrating that user involvement and students learning *with* service users can be achieved at early stages in nursing programmes (Wood & Wilson-Barnett 1999). However, this must be built upon over time and pervade every aspect of curriculum design and delivery to avoid tokenism.

We would also suggest that promoting human caring qualities may include nurses being in touch with their own mental health and periods of distress. It is notable that many users described a good mental health nurse as someone who 'had life experience', 'had experienced problems themselves' and 'were in touch with their own personal vulnerability'. A way forward in curriculum development may be to promote in students and educationalists the awareness 'that it could be, or, is us' (potential users, or people who *have* experienced mental distress). This would enable professionals to get in tune with the kind of help they would like to receive, and also what has helped them if they have experienced mental distress. It is also important to recognize and value the overlaps between service users and service providers (Francell 1996, Masching 1996, Smoyak 1996, Swan 1999). Educationalists and nursing students may also be service users but may not always make this information public. This experience should be validated and supported rather than devalued.

The issue of how human caring qualities can be protected must also be addressed. Findings revealed that participants considered that students usually started out as 'naturally caring' but once qualified were 'corrupted' by working in the mental health system. This view particularly related to hospital based contexts where nurses were described by users as disempowered by poor working conditions, under resourcing of the health service and medical model dominance. Other authors have noted that professional stress associated with a constant confrontation with mental distress and a lack of support results in nurses defensively distancing themselves from service users (Brandon 1991, Smith & Hart 1994, Wood & Wilson-Barnett 1999).

It is notable that while users viewed the hospital system as corrupting human qualities, work in the community appeared to redeem these qualities. The majority of participants were more positive about their contact with Community Psychiatric Nurses (CPNs). This finding is consistent with other research indicating that users tend to evaluate in-patient care more negatively than community care (Rogers *et al.* 1993, Beeforth *et al.* 1994, Lovell 1996, Lothian Health Council 1996). Some users described contact with the same nurses in the hospital context and later as CPNs and suggested that in the community context, the nurse's desired human qualities reappeared.

Educationalists may need to re-examine what comprises the practice experiences that will make students good mental health nurses and increase placement experiences in community based (statutory and nonstatutory agencies) and user led organizations.

Perhaps educationalists, students and users also need opportunities, or a forum, to confront their differences and user involvement in the curriculum could be a radical means of achieving this. We would suggest that nurse educators can productively use the issue of conflict in the curriculum rather than be defeated by it. The curriculum should not aim to conform conflicting views and reach consensus. Rather, the process of education should make conflict explicit in a climate that promotes debate and mutual respect.

Issues of representativeness

There are two aspects to the 'representativeness' debate in research of this nature, the first being whether the group recruited represented a methodologically sound research sample. In this case the research team acknowledge potential criticisms on the basis of the 'representativeness' of the users we consulted. The sample was small and we did not give a voice to all relevant and interested parties. It is also worth noting the methodological weaknesses of the study, with the second aspect of 'representativeness', being researchers' ability to consult and involve a range of participants to ensure representation of breadth and diversity of experience.

In the study we made the mistake of considering mental health service users a homogenous group with similar experiences and views. This mistake perhaps also reflects professional and patronising attitudes towards mental health service users as homogenous rather than unique individuals. It became clear as data collection progressed that, of course, different people hold different views. People consulted in users' forums tended to be much more critical of mental health services and nurses and proposed an active role in curriculum design and delivery. People who attended 'drop in' centres tended to be slightly less critical of services and did not appear to desire an active role in the curriculum. The suggestion was made (by service users attending 'drop in' centres) that consultation and involvement should be left to the 'experts', the 'experts' being user forum members and activists. One could argue that this reflects a perception among users that user activists are empowered to represent other users' views. Nevertheless the researchers acknowledge the risk of the people we consulted becoming the 'unelected representatives' of all mental health service users. In turn there is the risk that the researchers become the unelected rep-

resentatives, speaking, from the basis of a limited study, for all service users.

Beresford (1994) points out that one of the concerns most often raised by service providers is the 'representativeness' of service users. This is a contentious issue and many people in user organizations feel that their representativeness is challenged by service providers to invalidate what they say, or exclude them. Beresford points out that a double standard may be at play here with the representativeness of policy makers and professionals rarely challenged in the same way.

The debate about representativeness highlights a number of issues for user involvement in education. Most importantly it must be acknowledged that the views on 'representativeness' which are held by service users may differ from those held by professionals and researchers. If user activists are seen by other users as the most willing, and able to speak on behalf of service users, who are we (as professionals) to question this? The issue of representativeness must be broadened and debated in a way that informs educationalists and students rather than inhibiting their understanding. 'Representativeness' is likely to confront mental health professionals in every sphere of their working life. It is worth highlighting that there is no agreed meaning for 'representativeness' just as there is no 'one' service user voice. However, Beresford (1994) points out that most service user organizations are democratically constituted and, like other organizations, elect representatives in a democratic way. Users in our study generally considered that user organizations did represent users' agendas as a whole. Thus, we suggest that initially attempts to involve users in the curriculum should focus on working with user organizations and activists as these are the people most motivated to be involved, and most able to represent user views.

Issues of involvement versus tokenism

Education is not immune from current debates surrounding the confusion and difficulties encountered in attempts to involve users in mental health services (Campbell 1997, Hopten 1997, Mawhinney & McDaid 1997).

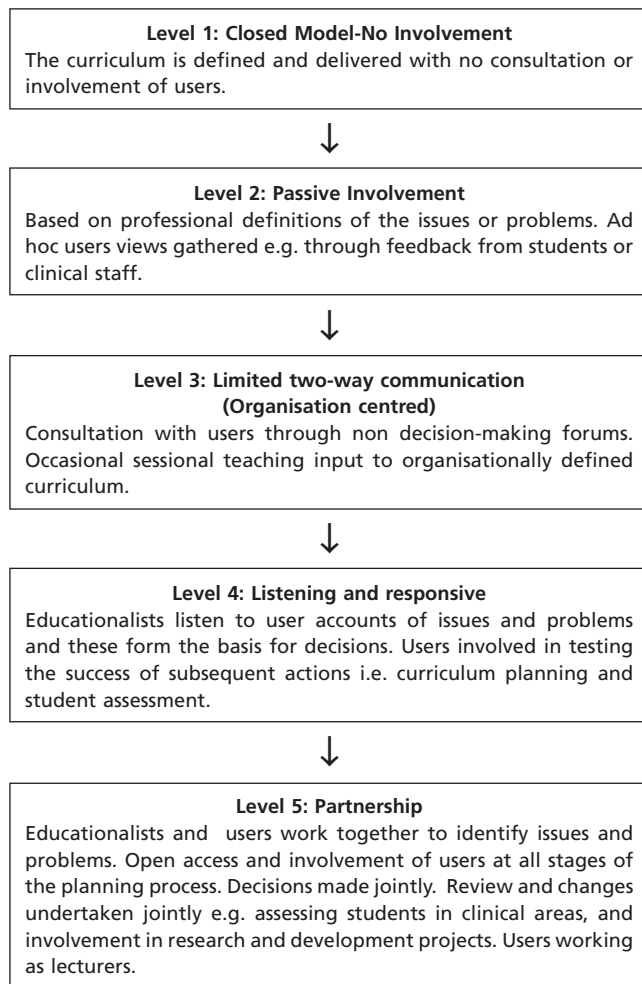
The ENB (1996) note that for user involvement to be a positive and active process it must be underlined by the key principles of consultation, negotiation, partnership and mutual respect. However, the challenge of achieving true involvement in the curriculum, rather than tokenistic consultation, is huge.

During the process of the study we began to realise that while there was value in asking users about their views of mental health nurses, we were failing to adequately address fundamental issues of involvement. We became aware

during negotiations for research access and during data collection, that user consultation is now extensive. Although this was generally viewed positively by participants there was also the sense that consultation led to limited 'real' involvement and influence.

One way of conceptualizing user involvement in the curriculum is in terms of a continuum, with each stage moving towards the 'partnership', so often expressed in policy rhetoric, but so rarely observed in practice. A continuum of involvement (see Figure 1) adapted from Goss & Miller (1995), for application to the educational context, provides a useful means of considering the issue of involvement.

The ENB (1996) point out that user involvement is not about 'slotting people easily into the existing curriculum'



Adapted from: Goss, S. and Miller, C. (1995) **From Margin to Mainstream: Developing User and Carer centred community care.** York. Joseph Rowntree Foundation.

Figure 1
A continuum of involvement.

(which would equate to Level 3 on the continuum of involvement). Rather it involves a radical approach to challenging and shifting the traditional power base and achieving involvement at the levels of curriculum planning, curriculum delivery, curriculum assessment (including assessment of students) and curriculum evaluation (Level 5 on the Involvement Continuum). It is notable that most reports of user involvement in professional education relate to involvement at the consultation or delivery level (Forrest *et al.* 1998).

If, as the ENB (1996) suggests, involvement requires a radical shift in traditional values and power bases then the process of achieving user involvement will necessitate challenge. This means that educators will not just have to challenge their own values and assumptions, but also challenge the wider institutional structures, systems and values that pervade academic and health service organizations.

To achieve a 'listening and responsive' level of involvement (level 4 of the continuum) requires that 'Users are involved in testing the success of subsequent actions, i.e. curriculum planning and student assessment'. Beresford (1994) suggests that service user involvement in education may have far reaching effects. There are inherent inequalities of power between service users and educationalists and similarly, there are inequalities of power between lecturers and students. Students often feel disempowered in relation to trained practitioners and educators. If innovations such as user involvement in selection interviews and student assessment are introduced there is the risk of disempowering students. Morgan & Sanggaran (1997) report the impact that mental health service user involvement in student assessment had on student performance. One student in their study reported spending most of her time trying to appease clients to gain a positive assessment, while other students reported that they did not value user involvement in the assessment process.

Several issues need to be resolved, for example, whether users are qualified to give feedback to students, and if so, the validity of such feedback. The challenge will be to establish clear criteria for user involvement. Users' rights may need to be protected, as it could be argued that if people are in hospital experiencing acute mental distress, the last thing they may need is the added burden and responsibility of assessing students. However, if such criteria are imposed this will result in limits being set for those people eligible to be involved. As Morgan & Sanggaran (1997) point out, setting criteria for user involvement in student learning means that the notion of empowering users becomes conditional by empowering only the selected few.

Curriculum innovations that promote user involvement have to be carefully considered, strategically planned and

introduced in a way that includes the agreement of all parties, including students. It is tempting to imagine that educators can easily progress to the 'Partnership' level of the 'involvement continuum', however, this would be naive. Raising these concerns does not mean that this cannot be done, but the point is stressed that this has to be worked towards carefully rather than rapidly implemented.

Conclusion

This paper has discussed issues surrounding service user involvement in preregistration nursing education. It has been proposed that, while the issues raised are challenging, they should not defeat educationalists, rather the issues should be made explicit throughout the curriculum.

We would suggest that a coherent and strategic approach has to be taken to achieve user involvement in education and cannot just be 'added on' to existing programmes. The research was set within a policy context that rhetorically promotes user involvement in almost every aspect of mental health service planning, delivery and professional education. The advice to 'involve' is plentiful but practical points about how to achieve this are few.

Good practice statements promoting user involvement suggest that this involvement should run the whole way through the curriculum (ENB 1996). It is pertinent to point out that educationalists receive specialist training, institutional support and importantly, financial remuneration to perform their educational role. We cannot promote partnership, involvement and equality between educationalists and user groups unless service users are prepared, supported and remunerated in the same way as educationalists. User involvement in education also requires training and support for educationalists and students to enable them to respond to changes resulting from greater user involvement.

This research put a group of educationalists in touch with users' views and enabled us to establish meaningful links with user groups, in a way that has already informed our curriculum and our practice. It is noted that the study was small in scale and had several methodological limitations. Nevertheless, the findings and issues raised during the research process are considered to merit radical responses which will ultimately influence the whole curriculum. An 'involvement project', supported by the National Board for Nursing Midwifery and Health Visiting for Scotland, is currently ongoing. The research has now evolved to a strategic planning stage and a strategy for user involvement is currently being developed and evaluated via a partnership project between service users, students and lecturers.

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