

Participation In Nurse Education: The PINE Project

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Abstract

Service user involvement is called for at every level of NHS delivery in the United Kingdom (UK). This article describes a model of service user participation in the development of mental health nurse curricula in a UK university. Using a research model of participatory action research, the Participation In Nurse Education (PINE) has now become mainstream in the mental health branches at the University. Service users led the design and implementation of the teaching sessions and led the data collection and analysis. Research participants were the service user trainers and the student nurses who were involved in being taught in the early stages of the project. The benefits of the work to both trainers and students are identified as well as some of the difficulties.

Key words

Mental health nurse education, participatory action research, service user involvement, student nurses

Introduction

This article describes a model of service user participation in the development of mental health nurse curricula in a UK university. Originally designed as a three-year participatory action research project, the Participation In Nurse Education (PINE) has latterly become mainstream in assuring the participation of service users in curricula design and teaching undergraduate mental health nurses in a UK university School of Nursing. It was as long ago as 1994 in the review of mental health nursing, that models of involvement of service users were called for (DH, 1994). Whilst there has certainly been plenty of activity to attempt meaningful involvement in the UK, there has been little in terms of research evidence to support such initiatives, especially those of a strategic nature.

The over-arching methodology for the project is participatory action research (PAR) (Kemmis and McTaggart 2000), utilising qualitative evaluation methods (Patton 1997; Greene 2000). PAR emphasises collaboration and permits the researchers and the participants to work together in partnership. This was a pivotal aspect of the philosophy and practice of the project. Ethical approval was obtained from the local ethics committee.

The PINE project was created as an action research project to fully involve service users in both curricula design and the development of teaching sessions designed, written and delivered by service users themselves. The tangible result of this project is the existence of four teaching sessions regularly delivered to undergraduate mental health nursing students across four centres in a region of the East Midlands in the UK. The development of the project has been a complex process with cycles of evaluation by those who have participated in the project. The design and implementation has taken three years and important lessons have been learned, as the model has been refined during this period. The project is reported in four distinct phases, and in terms of the participatory action research (PAR) process, each phase was concluded by the evaluation of the phase by the research steering group. The four phases were:

1. Recruitment to the research group
2. Development of the teaching materials
3. Implementation

4. Assessing the impact upon students and trainers

Following a brief review of the relevant literature, these four phases form the structure for the rest of this article followed by a brief discussion and conclusion.

Background

It is generally recognised that modern day challenges to inequalities in power between patients and professionals in the United Kingdom came from the rise of user groups in the 1980s (Brandon 1991; Campbell and Lindow 1997; Rogers and Pilgrim 1991), such as 'Survivors Speak Out'. Patient and public involvement in mental health and social care has continued to be driven by the service user movement in the United Kingdom which has campaigned to have the voices of service users heard, and by central government policy which supports involvement (for example, Department of Health 1997; 1999; 2006). There is now a duty in law placed on the National Health Service to involve and consult patients and the public in decisions about health services (Great Britain 2001).

Involving service users in nurse education reflects the philosophy of client-centred care and empowerment, which respects the need for service users to have a say in decisions that directly affect them. Furthermore, it allows service users to influence students in the formative years of their nursing careers by providing expertise from their experiences of receiving mental health services, which complements the 'scientific' emphasis of nursing curricula. Happell and Roper (2003) found that when a consumer academic was involved in classroom teaching, the students recognised a need to listen to clients and were reminded to view people with mental health problems as people rather than illnesses. The results of a comparative study by Wood and Wilson Barnett (1999) in which students responded to a video which simulated the assessment process, showed that the students who had had exposure to service users in the classroom were less likely to use defensive language and were more likely than other students who did not have the service user experience, to show greater empathy towards people with mental distress on the video. However, as Forrest et al (2000) suggested in exploring the issues of service user involvement in nurse education, a strategic approach should be taken in the curriculum.

Whilst the literature is generally positive about involving service users in various health and social care education initiatives, such as teaching or curriculum development (Repper and Breeze 2006; Tew et al 2004), there have also been some challenges to the process. Some health professionals, for example, have found the involvement of service users threatening (Glenister 1994) or causing an offence to their professionalism (Felton and Sticklely 2004), whilst others have made 'excuses' to avoid involvement (Crepaz-Kaey et al 1997; Basset 1999). In terms of the student experience of service users as teachers, a minority of students have been reported to find the sessions less than beneficial (Khoo, McVicar and Brandon 2004) or as a waste of time (Happell and Roper 2003).

None of the studies cited here give details on how or if service users had been prepared for their role and none involved service users as researchers. Furthermore, as Repper and Breeze (2006) note, little is known about the impact of service user involvement in nurse education on nursing practice. An exception is a recent study by Rush (2006) who reported specific mechanisms and contexts that led to insight and positive action by students who had received teaching from mental health service users in the classroom. Historically, psychiatry has used service users as medical specimens to help educate student doctors. Although this form of 'educational voyeurism' may be considered abusive, it was a crude attempt at evoking some form of empathy within the student doctors. The PINE project has attempted to evoke the empathy without the abuse.

Models of involvement

Involving service users in research as participants rather than as subjects has been developing since 1996 when a model of 'user focused monitoring' was produced by the Sainsbury Centre for Mental Health (SCMH, 1998). The model enabled research to be conducted by people who used mental health services to evaluate the experiences of other people using the services (Rose 2001). Similarly, Faulkner and Layzell (2000) reported on user-led research that explored people's strategies for living and coping with mental distress. At the present time groups such as SURGE (2008); SURE (2008) and INVOLVE (2008) seek to promote the involvement of service users and most recently the Royal College of Nursing (RCN) has produced guidance on how nurses can involve service users in research (RCN 2007). The PINE project addressed the limitations of other studies through a participatory process where service users were partners in research and teaching (Roberts et al., 2007).

Historically, the university department concerned had ad hoc arrangements for "service user experts" or "representatives" to contribute to curriculum advisory groups and occasional teaching sessions. Making Waves is an organisation made up of people with experience of mental distress. It was set up to use teaching and research to try and change the way that people think about 'madness'. Making Waves were commissioned to work with the School in order to develop a model of involvement that would become meaningful for nurse education.

A group that comprised service users and academics, therefore met for several years before appropriate funding was identified. Funding for the PINE project however was secured by the university lecturers from funds specifically allocated for the development of educational practices within the university. This new stream of funding therefore permitted the potential for the development of a new model of working and Making Waves were very keen to become involved in a three-year participatory action research project developing a new model for what we then referred to as "service user involvement" in mental health nurse education.

The recruitment to the research group phase

From the outset, it should be noted that in the development of the PINE project, we did not seek to fully involve people who describe themselves as carers in the processes. Much policy directive in the UK joins together "users and carers" as if they are a homogenous body of people and have one agenda. From our understanding of the relevant research literature however we concluded that the respective agendas of people who use mental health services and those who see themselves as carers can be quite different, certainly in the UK. It was considered therefore that the priority should be a model that fully involves the participation of service users in curricula design and teaching delivery.

A steering group was formed that met approximately monthly for three years. The steering group comprised approximately half academics and half service users. Minutes were recorded and contribute to the data of the action research process. As the group commenced regular meetings and designing the project, there were many philosophical discussions that debated the nature of the relationship between the academic professionals and the people who used services. It was decided early on, that we would abandon the notion of "involvement" as it inadequately addressed the power relationships. It was decided therefore that the project would not develop a model of involvement, but rather, a model of participation (some of this philosophical debate is articulated in Stickley, (2007)). The outcome of these early discussions was therefore to transfer the majority of the funds to Making Waves so they could have control

over the development of the teaching materials. An independent training consultant was appointed who would lead on the development of the teaching sessions (this is fully dealt with in Roberts et al., 2007). This training consultant (SR) is the third author of this article.

The development of the teaching materials phase

Through community networks, SR recruited approximately 16 people who had all used or currently use mental health services. This group met over a period of several months and developed their own aims and philosophy for the group that would guide the development of the materials, these were:

- To educate student mental health nurses from a service user's perspective
- To make sure all service users and relevant staff understand the project's goals and aims
- Identifying the issues and the development of the teaching materials
- The sessions stress the importance of student nurses' potential impact on service users' lives
- All development sessions should be a welcoming place for service users to attend

The aim of the development sessions was to involve and actively support service users in the process of developing teaching materials. In order to achieve this, first stage issues were agreed as:

- Develop relationship with existing service users who have delivered training sessions within the mental health curricula
- Make contact with new providers and service users who wish to take part in the development and training process
- Select four key educational areas for development
- Develop a realistic timescale

An initial open day was facilitated and sixteen service users attended. Participants were invited to identify how their experiences and knowledge could be used to highlight the ways in which the four educational themes could be further developed. The four educational themes were decided upon that would later become the teaching sessions:

- Strategies for survival: what do people do to keep well at home, what helps to cope with stress, to spot early signs of being unwell, or to get through a crisis?
- Professionals on tap not on top: professionals can help, or make things more difficult – how can professionals help people with information and support, instead of trying to control people or telling them what to do?
- Diagnose this: see the person, not the label – everyone is an individual, and everybody's mental health goes up and down, whatever diagnosis we might or might not have.
- Living on an acute ward: going into hospital, coming out, and everything in between – experiences, survival tips and how nurses can help – taught by people who've been there.

Following the open day, the group became arranged into four work streams to develop the teaching sessions. The number of service users assigned to each of the teaching areas were as follows:

- Strategies for survival (nine people)
- Living on a acute ward (six people)
- Diagnose This (ten people)

- Professionals on tap not on top (seven people)

Each educational theme had at least 12 hours devoted to the development of the specific theme identified and the teaching sessions were each designed to last two hours. In order to develop the ownership of the themes critical attention was paid to listening to the participants, their views, needs and their wants. It was agreed, at an early stage of the development process, that participants preferred the term 'facilitator' rather than 'service user'. The consensus was that service users felt they were often just 'wheeled' in when requested, whereas the term 'facilitator' put service users on an equal footing with the professionals.

The implementation phase

The lecturers who were involved in the project (first and second authors, TS and BR), were also involved in the management and delivery of the diploma of nursing programme at the research site; permission from the relevant authorities to implement the teaching sessions was therefore straightforward. Nevertheless, a plan for implementation was agreed and during the first semester of 2003-2004 Diploma of Nursing Mental health Branch programme. All four teaching sessions were piloted amongst approximately 60 students at two centres (Nottingham and Lincoln). Much work was committed to identifying the support needs of service user facilitators. All facilitators underwent some form of "training for trainers" programme to help equip them for teaching (this is described in more detail in Hanson and Mitchell, 2001). The facilitators also agreed from the outset that they would prefer not to be accompanied in the classroom by teaching staff. It was agreed that sessions would be facilitated by two people on every occasion wherever possible and service users were paid according to the School of Nursing guidelines for payment, which follow the principles of the later published *Reward and Recognition* document (DH, CSIP 2006).

Assessing the impact upon student learning phase

In order to assess the impact of the teaching sessions upon students and on facilitators, a small service user sub-group was identified. This group developed qualitative research questions for focus group and individual interviews. It also undertook the research and analysed the emerging data. This was an exercise in participant research; the service user researchers were also part of the facilitator group. The group identified their research question: "From an emancipatory service user perspective, in what ways does user involvement in nurse training affect the perceptions of the student nurses and service users involved?". Four focus groups were conducted amongst students prior to the teaching implementation and a further five focus groups were conducted amongst students towards the end of their education. In total about fifty students participated in the focus group process. Additionally, students were asked to complete questionnaires at the end of every teaching session delivered by the service users. Questionnaires were also completed by the facilitators before and after each teaching session. Some facilitators were also interviewed before they delivered any teaching. In addition to the interviews and focus groups, the researchers also maintained research diaries that enabled critical reflection of the research process and outcomes. The contents of the diaries were also available as research data.

Students taking part in the focus groups took responsibility for writing down key points from their discussions. The qualitative data from both the focus and questionnaires were analysed by the research group in a collaborative and equal manner. Themes were identified from the qualitative data by literally cutting and pasting paper copies of data.

Findings

Students' perceptions of mental health service users teaching on the nurse training prior to any training delivered by service user trainers.

All of the students interviewed, were positive about the idea of teaching being delivered by service user trainers. This was however, tempered with some anxieties. Some students thought that service user teachers might have their "own agenda" and these are some of the questions students asked:

'Are service users taking learning away from theory?'
'Is their input valid?'
'Are service users biased?'
'Are they receiving appropriate training?'
'Is this a gimmick?'

Generally though, students thought the experience would be informative, educational, and interesting. In particular, students recognised the significance of the experiences being shared was "first hand".

"We can empathise more because the service users have a genuine insight into mental health issues"

Some students believed that having service user input would have a positive impact on the care they would give in the future.

"it helps students to deliver holistic, i. e. person centred care and listening to the 'lived experience' hits home. Better than reading about it..."

They believed that the PINE project might help to change attitudes. The students also felt it would improve empathy and communication skills.

"The session provoked many feelings: empathy, sympathy and respect"

Service user facilitator perspectives of students prior to any training delivery.

Prior to delivering the sessions, facilitators were 'looking forward to the challenge'. They felt confident because of the research and preparation that had gone into the preparation. The sense of responsibility was strong and there was some anxiety

"Because I have done some training before, I don't feel as nervous as perhaps other will feel. When I first did it I was extremely anxious but I do feel a little nervous because there are going to be a lot of students and I'm not used to big groups..."

Service user facilitators were keen to make a real difference to students' education:

" I hope that I will be able to contribute usefully to nurse education. I hope that in a small way I will be able to make a bit of a difference."

The trainers were 'excited' and 'generally upbeat' but 'still apprehensive in case things went wrong'.

Still apprehensive in case things go wrong, but generally upbeat.

"I'm apprehensive but looking forward to getting on with it."

"I feel nervous but knowing I have an inner confidence to rely on."

"I do feel nervous about what a big group and if it will all go to plan."

"I also feel a lot of pressure not to let other members down."

There was some apprehension whether or not the sessions would be taken seriously:

'Will they understand the point I am trying to make or if they will think I am a crazy person?'

"I'd like the students to view me as a human being and view me as intelligent with something to offer and listen to. I would like them to view me as not a Mental Health Service User but someone who is capable, reliable and honest but at times experiences mental distress. Somebody who is as unique as anybody on this earth.'

One trainer however was less sensitive:

"I couldn't care less as long as we get them to think about how service users cope with illness and how nurses support and facilitate well being.'

There was some concern by trainers about their own well-being in case they were not feeling too well. However they felt that security in knowing the sessions were well planned:

'It's been planned well so that's ok'; and I feel comfortable with my co-trainer.

One trainer acknowledged the potential for being patronised:

"I think the students will view me as a service user. With a label and a diagnosis. I think they will listen and take on board some of what is being said but at the back of their minds they will dismiss some of it because they will be viewing me as someone who is mentally ill and unstable."

Students' perceptions of facilitators' teaching after the sessions had been delivered.

The students were asked what their feelings were about coming to these sessions and what they thought about them. The student comments were largely positive, this could have been skewed by the service users conducting the research were also the trainers. Generally, the students' found the sessions to be enjoyable, interesting, informative, insightful, well presented and well run. The sessions were meaningful to the students, thought provoking and enlightening but also fun.

"It gave me an improved understanding of service user experiences because they have a genuine insight into mental health issues. Good to gain personal first hand experiences and perspective from service users making the theory real."

Students on the whole gained a better understanding and insight of the reality of being a service user. It refreshed those who already had some knowledge. Students now saw service users as ordinary people trying to cope with life:

"It's helped me to see the person not the illness/diagnosis."

Students claimed to have gained empathy, knowledge and cultural awareness from the sessions. Students believed this work would impact upon the care they give:

"We need more sessions involving people who use mental health services – only then can we provide better care and acknowledge mental health problems"

The students felt they had learnt about various practical, simple, easy to implement and alternative coping strategies, different interventions and how they could help recipients of services. They said felt clearer about the concept of survival and the need for more activities and the need to take a holistic view. They learnt about different views of stressors and new ideas about people's feelings. The training helped the students to reflect on what had been learnt. The training also equipped the students with awareness of the service user perspective and ideas to consider when working with clients: changing the student approach for good.

Service user facilitators delivering training are seen as having:

"good insight/knowledge and strength/courage in standing up in front of people to share their experiences".

"They are innovative... and helping to deliver care. It is good for them to give their ideas and get their point across."

The training improved the students' understanding of the service user experiences because of the first hand experiences:

"They have a genuine insight into mental health issues... It was good to gain personal first-hand experiences and perspective from service users, making the theory real."

"My view of service users facilitators is that they provide first hand information that may not be found in text books."

Reflection by researchers after the resulting themes emerged.

Generally, service user trainers were satisfied with their performance:

"I felt very nervous beforehand, but the session went very well."

"Now I'm excited about doing more. It gave me a great feeling of satisfaction and pride."

"I feel it was worthwhile, enjoyable both for myself and the students, I am happy to be a facilitator – I enjoy the teaching."

"The delivery was fine. We followed our agenda and everything worked well. We got through our material more quickly than expected, but that just meant we could have an early finish."

There were some difficulties:

"I feel it was more difficult than the last session. Only 15 students, as opposed to 44. Should have been easier but felt more intense. Also, because this group were 2nd year Mental Health students, I felt there was more pressure on us."

"I was worried because I am not feeling too well."

Students expressed a broad range of views and were mostly positive of service user involvement in general. There were some negative views prior to training delivery but none afterwards and positive expectations were met. The answers given post-training were far more comprehensive and thought out by the students than prior to training. Whilst they knew involvement by service users was a good thing in theory, they remained nevertheless apprehensive. Following the training sessions however, it appears that their apprehensions were allayed.

Conclusion

This short article is a snapshot of what has been a developing project over a period of several years. Many people have been involved in one way or another and this report does not do justice to the work and complexities that a project such as this involves. Our original intention was to develop a piece of work that was genuinely collaborative and that would impact upon the learning of student nurses to influence their future practice. Whilst the findings of our research are mostly positive, longitudinal research is necessary to establish effect over a period of time. Furthermore, we would be naïve not to consider the potential impact of professional socialisation once the student nurses qualified and became staff nurses; therefore, further research into this area is also needed.

Whilst we have achieved much, there is much more yet to do. Our project has only extended to the development of four teaching sessions. Whilst these are of great value, perhaps there are many more sessions and modules to develop to help achieve our goal of influencing nursing practice in the future.

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