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**Participation in Practice
A Review of Service User Involvement in Mental Health Nursing**

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Participation in Practice: A Review of Service User Participation in Mental Health Nursing

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Abstract

Aim: To explore the current literature on service user participation in mental health nursing care and the effectiveness of participation practices.

Background: Service user involvement in mental health nursing is a requirement of current practice including research and education. A review of the literature was undertaken as part of a research study on involvement practices in mental health nursing.

Method: Original research documents were explored that related to participation in mental health nursing practice. The review included mental health nursing research, education and practice in order to capture the extensive areas of practice.

Findings: There are various levels of participation occurring within mental health nursing. The review identified that there is a need for training and knowledge development in order to become familiar with the different levels and develop participation in practice.

Conclusion: Information and training in mental health nursing would develop knowledge of participation practices and empower service users to have more control.

Key words: Mental Health Nursing, Service User Involvement, Participation.

Introduction

Recent reports by the government appointed auditing body, the Care Quality Commission (CQC), in the UK, found that less than 50% of service users felt that they had been involved in acute care, in addition to only 59% of service users saying they were involved in their care plan in the community (Santry 2009, Care Quality Commission 2009, Healthcare Commission 2008). Such reports indicate a trend in the lack of participation in mental health nursing despite professional and political drives to encourage it (Harrison and MacDonald 2008). This paper will outline a shorter version of a review undertaken by the author as part of a research study on service user participation in mental health nursing. For the purpose of this paper 'practice' includes participation in individual and service development planning which is often used interchangeably in policy documents.

There is no doubt that service user and carer participation is firmly embedded in the policy documents that influence mental health nursing practice. In particular, The Ten Essential Shared Capabilities (Department of Health 2004), From Values to Action: The Chief Nursing Officer's Review of Mental Health Nursing (Department of Health 2006) and more recently New Horizons: A Shared Vision for Mental Health (Department of Health 2009). More recently in education, the Nursing and Midwifery Council has declared service user and carer participation to be a required standard in the design and delivery of all pre registration nursing programmes (Nursing and Midwifery Council 2010 Requirement R5.1.2). Any review of participation in practice therefore must acknowledge the political drive for shared power and decision making in mental health care and this will be discussed further below. The policy background will be followed by a brief account of the literature found and a discussion of the main points. In concluding this paper, recommendations will be made for the development of participation in practice.

In order to clarify terms used, the words 'service user' will be used to include carers and to represent all those involved in receiving a service from mental health nurses.

Political Approaches to Service User and Carer Participation in Mental Health Nursing

Beresford and Branfield (2006) identify that despite the general consensus of opinion that a market-led, consumerist approach to national healthcare has been agreed by all of the political parties in the UK, there is still a separation between service user involvement and the quality agenda. Extensive reviews have been carried out on participation in mental health such as the National Institute for Mental Health in England (NIMHE 2003) review of all available literature between 1997 and 2000. NIMHE (2003) identified 650 documents on service user participation in mental health practice in England, and found that there were a number of benefits, as well as barriers, to service user participation depending upon a variety of factors. In general, NIMHE (2003) found that there was a need to address issues that prevented participation in addition to developing closer partnerships and relationships between service users and professionals. They suggested that this could be achieved by exploring the strengths of service users rather than the weaknesses and by involving the wider community in developing services and practice. NIMHE (2003) suggested that Arnstein's (1969) ladder of participation could help practitioners and organisations to identify areas of participation available and accessible to mental health service users. The ladder proposes a number of rungs or stages including citizen control, delegated power, partnerships, placation, consultation, informing, therapy and manipulation. The first three are considered to demonstrate citizen power, while the middle three demonstrate tokenism. The last two demonstrate non participation where no participation took place and care was prescribed. Although not set in the mental health arena, Arnstein's (1969) ladder provides a comprehensive overview of involvement and participation in which it should be noted that participation does not generally occur until the middle stages of the ladder and full participation and empowerment at the higher stages. A significant difference therefore can be identified between involvement, tokenism and participation.

Hanley et al's (2003) guidance for service user involvement in research, by the government supported organisation INVOLVE, suggests that such in-depth levels are not always necessary but may be required in some areas of practice. Hanley et al (2003), and other researchers, have used a modified version of Arnstein's (1969) work that reduces the ladder to only three stages: consumer-controlled, collaboration and consultation. Hanley et al's (2003) version is widely used in large outcome studies such as the NHS Health Technology Assessment Programme (Oliver et al 2004) and Cochrane Reviews (Nilsen et al 2006, 2010). Tew et al (2004) in their work on participation in higher education used a different ladder of participation that identified stages such as: no participation, limited participation, growing participation, collaboration, partnership. However Tew et al (2004) recognises that this ladder does not venture further than the participation stage and makes some suggestion for people to become more empowered. Interestingly, the power imbalance is less evident in these more recent measures and there is a danger that empowering practices that lead to full control may become obscured. In 2003 NIMHE identified that concerns should be raised around what level or power in the participation processes service users actually had. If left unidentified, expectations may conflict with service providers including managers, nurses, researchers and lecturers. This continues to be a challenge in mental health care with more recent reviews highlighting similar themes (Nilsen et al 2010, Sainsbury Centre for Mental Health 2010). Therefore, in order to ensure that all voices were heard this review used Arnstein's (1969) original ladder so that empowerment and tokenism in mental health nursing practice could be identified.

Exploring the Literature on Service User Participation in Mental Health Nursing

The literature review was carried out using professional journal search engines such as Pubmed and Swetswise, as well as The Cochrane Library and hand searching of journals available. An internet search was also carried out for research reports not normally found in professional journals. Such research is also known as grey literature (Greenhalgh 1997) and included charities and organisations such as The Sainsbury Centre for Mental Health, The Joseph Rowntree Foundation and the Health Technology Centre. The keywords used included service user involvement, participation and mental health nursing. All original research articles were included that focused upon mental health service user participation in mental health nursing research, education and/or practice, between the years of 2000-2009. Exclusion criteria were set to avoid confusing findings with other areas of mental health and nursing practice including forensic, children or older people's mental health that have additional roles and responsibilities attached, as well as social work and other mental health professions. The review outlined below was carried out for the purpose of exploring the literature on participation in mental health nursing and does not claim to have explored systematically all areas of research on the subject. Systematic reviews carry much stricter guidelines and can exclude grey literature and service user-led research (Nilsen 2010, Repper and Brooker 2004, Greenhalgh 1997). In total 22 papers were reviewed and identified both qualitative and quantitative research (see table 1). The findings are discussed below in the areas of mental health nursing that include research and service development, education and practice.

Participation in Research and Service Development

In a user-led research report for the Rowntree Foundation, Branfield and Beresford (2006) found a number of uncertainties around participation practices. Doubts included funding and information being available and training and education being provided for service users and carers to have more control. Nilsen et al (2006) explored the quantitative literature and found that there was little evidence of service user participation influencing service development. However, Oliver et al (2004) explored participation in research and found that the level of control given to service users did influence the outcomes. Oliver et al (2004) recommended further research into the power imbalances in involving people in research. Hui and Stickley (2007) explored the power imbalance in service user participation and found that there were indeed discrepancies between the top down and bottom up approaches to participation. The voice of the organisation was found to be much stronger than the voice of the service users with consultation being used most frequently for involving service users in research and service development. Rose (2003), in a user led piece of research, also found that many service users did not feel involved and lacked information and knowledge of different processes. Involving people in research and practice may therefore be challenged by the level of participation and the support provided to become more involved.

Participation in Nursing Practice

Anthony and Crawford (2000) found that while nurses shared the same values and beliefs about participation with service users, they identified some barriers. A lack of resources and skills was identified and poor teamwork and the nature of acute illness were also found to be obstructive. More recently, Lakeman (2008) found that people did feel more involved in nursing care decisions. However, this depended upon developing good relationships with staff. Furthermore, factors that affected the level of participation included a lack of consultation and information.

Table 1

Authors, Title and Date	Methodology/Methods	Results
Anthony P; Crawford P. 2000. Service user involvement in care planning the mental health nurses experience	Qualitative Phenomenology – interview of 9 nurses	Shared values and beliefs about SUI Obstacles - resources, skills in diversity, acute illness and team working
Branfield F; Beresford P, (2006). Making User involvement Work Supporting Service user networking and Knowledge	User led Group discussions	Isolation a barrier Networking effective Knowledge not valued Diverse experiences needed in education
Cooper H; Spencer-Dawe E. 2006. Involving service users in interprofessional education narrowing the gap between theory and practice	New paradigm research - qualitative feedback from service users, students and facilitators	Improves understanding & application of theory to practice Improves team working and relationship building Unpredictable and uncertainty inherent within the process
Felton A; Stickley, T. 2004. Pedagogy, power and service user involvement.	Qualitative interviews with 5 lecturers	Power inequalities Requires change in structure Committed nurses in the minority
Hird M. 2007. Service user involvement in mental health assessment	Grounded Theory	The relationship of autonomy and benefits needs addressing The process of assessment is not efficient in eliciting full stories
Hui A; Stickley T. 2007. Mental Health policy and mental health service users experiences on Involvement: A discourse analysis	Discourse analysis of current literature	Discrepancies in definition of involvement Power imbalance in implementation Resource imbalances
Khoo R; McVicar A; Brandon D. 2004. Service user involvement in post graduate mental health education	Questionnaire and interviews of students	Benefits include changes in practice alternative views of practice and changes in attitudes towards involvement Some disadvantages included bias of service user
Lakeman, R. 2008. Family and carer participation in mental health care: experiences of consumers and carers in hospital and home settings	Survey of service users and carers	Support and access to services most important Diversity and respect not always addressed
Lamers J; Happell B. 2003. Consumer Participation in mental health services: looking from a consumer experience	Participatory Action Research with consumers	Involvement can be effective but needs to recognise diverse needs of service users Need clear processes to enable involvement

Authors, Title and Date	Methodology/Methods	Results
Miller L. 2006. Redressing the balance : User involvement in the training of mental health nurses in Wales	Focus groups with service users, student nurses and lecturers	Values and attitudes of staff Power imbalance Activities and occupation
Nilsen et al 2006. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material	Intervention review of RCTs	Little evidence for the effectiveness of consumer involvement in healthcare decisions at population level
NIMHE. 2003. Cases for Change: User involvement	Review of the literature	Methods for overcoming barriers to user involvement include: - Individual relationships - Genuine partnerships - Genuine involvement in all areas - Practical barriers need addressing - Focus on strengths of service users - Develop user led services - Wider involvement in education etc
Oliver et al 2004. Involving consumers in research and agenda setting for the NHS: developing an evidence based approach	Systematic Review	Individual contribution, collective consumer action, linked to greater influence resulting in change to organisations
Owen C; Raey R. 2004. Consumers as tutors – legitimate teachers	Questionnaire attitudes and course evaluation	Attitudes changed in relating to service users Equal relationships developed
Piippo J; Aaltonen J.2008. Mental Health and Creating Safety: the participation of relatives in Psychiatric treatment and its significance	Grounded Theory	Primary - Shared understanding, new kind of relationship, being able to cope. Secondary - Exclusion, need for 1-1 relationship, whom or what can we believe, keeping the illness secret, Core - Safety
Roberts G; Hardacre J; Locock; L; Bates P; Glasby J. 2003. Redesigning Mental Health Services Lessons on user involvement from the Mental Health Collaborative	Action Research Study	One approach does not fit all The process of involvement is as important as the task Services users need support Staff need support Practical, cultural and symbolic barriers need addressing

Authors, Title and Date	Methodology/Methods	Results
Rose D. 2003. Partnership coordination of care and the place of user involvement	User led social survey	Lack of knowledge of CPA Lack of involvement in care planning
Rush B. 2008. Mental Health Service User Involvement in Nurse Education: A catalyst for transformative learning	Semi structured interviews/ group interviews	Transformative learning Emotive learning Different for placement learning
Simons et al 2007. A Socially inclusive approach to user participation in higher education	Observational case study	Effective role model Effective partnership working Tokenism and exploitation observed.
Stickley et al 2009. Participation in Nurse Education	Participatory Action Research	Improvement in student knowledge around coping skills, communication and empathy. Service users increase self esteem
Tee et al 2007. User Participation in mental health nurse decision making: a cooperative enquiry approach	Cooperative enquiry	Inhibiting factors – stigma, paternalism, diagnosis Enhancing factors – respect for culture and expertise and belief in individual potential.
Wallcraft et al 2003. On Our Own Terms: users and survivors of mental health services working together for support and change	Survey and interviews	Groups effective in providing support but want to be treated as people not labels, Power differences are an issue with nurses and treatment issues need addressing. Involvement only effective if genuine and nurses should make more of an effort to visit groups.

Piippo and Aaltonen (2008), in a similar study, explored the participation of family in mental health care services. They found that safety was a critical outcome of the process and that coping skills and relationships were important to service user participation. However, secrecy and stigma could prevent people from wanting to become more involved. The importance of relationships or dialogue was identified by Hird (2007) in a study of the assessments undertaken by community mental health nurses. Hird (2007) found that relationship development was restricted by the nurse's need to gather information. Similarly, in reviewing the quality of mental health care Roberts et al (2003) explored the patient journey and found that processes do not always provide the information people need. Roberts et al (2003) recommended a need to be aware that participation requires adjustment so that placation practices do not develop. In addition, cultural and practical barriers need to be addressed. In a similar study, Tee et al (2007) explored the barriers and promoting factors of service user participation with student mental health nurses. They found that stigma and labelling prevented collaborative working which could be addressed in education and practice.

The above findings are supported by Wallcraft et al (2003) who surveyed and interviewed members of mental health service user movements. They found that movement groups can

offer support and information to individuals but are often prevented from becoming more involved. Wallcraft et al (2003) suggested that service user participation on a group level is not valued because of the stigma and power that exists within the service. It is useful therefore to explore participation in other organisations such as education where the power imbalance should not be so evident.

Participation in Education

Simons et al (2007) found that where a particular post had been created in education to develop service user participation, feedback was mainly positive. In addition, developing a role model generated closer working relationships. Owen and Reay (2004) also found that in employing service users as tutors, students began to value their contribution.

However, Felton and Stickley (2004) explored service user participation in professional education and identified tokenism as an evident power imbalance where service users lacked information and support in developing their role. In contrast, Khoo et al (2004) explored postgraduate mental health education and found that participation could change attitudes and beliefs about service users thus addressing the stigma. However, Khoo et al (2004) also identified that where service users wanted to talk about bad experiences, students were less receptive. Lamers and Happell (2003) found similar themes when interviewing service users. They identified that while participation can be effective there needed to be some recognition of the diverse needs of service users and that there should be a clear process for achieving this. A later study by Stickley et al (2009) identified areas of practice that could be developed in nurse education. Their findings suggest that student's knowledge about coping skills, communication and empathy had developed and service users' confidence had improved. Similarly, Cooper and Spencer-Dawe (2006) evaluated participation in inter professional education with first year students and found that knowledge and understanding had improved. In addition, Miller (2006) evaluated mental health nurse training and found that the values and attitudes of nurses were an important factor in developing participation. Rush (2008) evaluated the participation of service users in education and suggested that proper training and preparation for service users and carers allows for transformative learning to take place. She described this as a reflective process where students were able to identify what has changed in their learning following the experience.

The above outline of the literature found many areas for consideration that will be discussed further below.

Participation in Practice in Mental Health Nursing

Mental health nursing is constantly being revised to meet the needs of both service providers and service users, therefore it is important to recognise such changes in practice. Bee et al's (2008) study of what service users wanted from mental health nurses included knowledge and relationship development skills. This requires mental health nurses to be able to involve service users and carers in all aspects of their care (Hui and Stickley 2007, Beresford and Branfield 2006, Nilsen et al 2006, Oliver et 2004). However, it appears mental health nurses may be pulled in a competing direction of meeting the needs of the organisation rather than the service user (Hird 2007, Rose 2003). Focusing upon organisational needs does not allow for a genuine narrative or dialogue to be created that can consider equally all contributions to service user participation (Carson 2001). A more balanced approach might require a shift in culture as suggested by Branfield and Beresford (2006) or simply a shift in thinking about how mental health nurses address service user participation. Conversely, encouraging people to become more involved does not guarantee participation and may even expose further the stigma and lack of power in practice.

While policies suggest that participation will improve the care provided this depends upon the relationships developed between service users and nurses (Khoo et al 2004, Hui and Stickley 2007, Bee et al 2008). Participation practices can lead to increased confidence and self esteem in carers and service users and in transformative understanding in students (Rush 2008). It is evident that collaboration or participation in practice is beginning to develop but it appears to have failed to acknowledge the shift in culture required. This shift includes the transfer of power and knowledge development and the increase in support needed to achieve this. Indeed, at a policy level there is a dearth of evidence to say that participation has had any effect at all (Minogue et al 2009, Oliver et al 2004).

The main trend in participation in practice appears to be the development of relationships that are trustworthy and supportive (Anthony and Crawford 2000, Lakeman 2008). Service users and carers are able to discuss personal issues with students and nurses that are often stigmatising and oppressive (Tee et al 2007). Such discussions when carried out in a supportive environment can lead to a changed understanding in students and practitioners (Miller 2006, Stickley et al 2009). The management of risk also becomes more evident when involving service users (Anthony and Crawford 2000), but where risks are identified there is the opportunity to put safety measures in place (Piippo and Aaltonen 2008). Service users who are acutely unwell should also have the opportunity to participate in their care but this might require an improvement in communication skills. Developing such skills in the classroom can help nurses to become more confident in their practice. Training and education must therefore be provided to all those who wish to develop participation practices (Simons et al 2007, Nilsen et al 2006, Beresford 2003).

However, a recent evaluation report by the Sainsbury Centre for Mental Health (2010) found that service users still suffer from a lack of information and training. This is an ongoing problem that could lead to a lack of effectiveness in involving service users and carers. The costs in terms of resources, money and time have been identified in this review as an issue of concern to both service users and nurses (Anthony and Crawford 2000, Beresford and Branfield 2006, Minogue et al 2009)

Stringer et al (2008) suggests that involvement practices that lead to participation and beyond can be measured using ladders of participation and other more robust outcome measures. However, in order for participation to be effective more effort needs to be made to meet the resources and training needs of nurses and service users and carers without which, participation will remain largely tokenistic. (Felton and Stickley 2004, Beresford and Branfield 2006, Rush 2008).

Conclusion

Changing the culture of mental health nursing practice will be difficult until the challenges of service user participation are properly recognised. Preparation and training for participatory practice needs to be in place to provide a supportive and reflective environment where transformative learning can take place. However, this may be especially difficult in the busy practice arena.

Such preparation will inevitably cost time, money and a secure knowledge that the support will be provided to everyone involved. Identifying early in any participatory project what is required and expected will allow mental health nurses to recognise their position on the ladder of participation and the level at which service users and carers can realistically contribute. Much of the research outlined in this paper has identified that many people in mental health nursing are working towards participatory practice. However, this now needs further research to demonstrate that service users and care are becoming empowered in the process.

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