A STUDY OF
SERVICE USER AND CARER INVOLVEMENT IN MENTAL HEALTH TRAINING, EDUCATION AND RESEARCH IN WEST YORKSHIRE

A Summary

March 2009

WHAT THE STUDY INVOLVED

A collaborative study, led by service users and carers, of service user and carer's involvement in mental health education, training, and research was undertaken. This comprised of a literature review and a scoping study across the 3 specialist mental health NHS Trusts and 4 Universities in West Yorkshire in 2008. The latter involved a survey of senior managers in all the organisations, interviews and focus groups with service users and carers involved in teaching and research.

The study examined the effectiveness of service user and carer involvement from the service user and carer, professional and policy perspective. It aimed to determine whether it was possible to define and measure effective and meaningful service user and carer involvement. It also sought to discover which processes and strategies were most effective in achieving meaningful involvement.

WHAT THE STUDY FOUND

The literature review identified a raft of policy and guidance, emanating from the Department of Health, advocating involvement but a lack of consistency in its application.

Service user and carer involvement is taking place across a number of areas within mental health education, training and research. However, it is still ad hoc and there is no clear methodology within teaching and training. Service user and carer involvement in research is also varied but there are clear methodologies identified, although they are not implemented with any consistency. Benefits of involvement in education and training, which were identified, primarily related to the addition of the user perspective and the impact on student practice. Benefits of involvement in the research process similarly included the user perspective and, in addition, increased relevance of research questions and research methodology, and improved staff recruitment. Benefits to the service user and carer were also recognised. Despite the high level of involvement activity barriers still exist and included: funding, lack of opportunities, lack of support and training, and failure to value the user perspective.

The study found that all the NHS organisations included had service user involvement policies in place but this was less clear for the Universities. Many service users and carers thought that the main reason for involving them in activities was because it was a mandatory requirement. Definitions of involvement covered a broad range of activity. Involvement for service users and carers covered a range of teaching, training and research activity but also included peer support and other support groups. NHS and University staff had a more instrumental view of what comprised involvement and described it as

active, meaningful partnership work which had value and impact. Service user and carer motivation for involvement could be categorised as altruism or personal gains.

> *'Engagement of people…..in influencing service design and developing service quality'.* NHS manager.

> *'To make sure that the focus of our courses and research reflects the needs, interests and perspectives of service users and carers'* University staff.

Organisations used a range of methods to recruit service users and carers. Despite this, all the service user and carer participants in the study had been recruited through personal approaches and were critical of access to opportunities. This invariably led to involvement in further activities further restricting the inclusiveness of the projects. Processes for recruitment tended to be informal and did not involve matching the skills of the user to the activity or vice versa.

> *'It seems that sometime's it's quite tokenistic and ticking a box, you can say that there was a service user at the meeting, not really taking on board what's being fed back in terms of peoples' experiences and what they really want'.* Service user.

> *'If I didn't have the illness I wouldn't have known because there's not enough information'.* Service user.

There was a broad range of involvement activity amongst the service user and carer respondents in the study. Only a very small number had any formal training or qualifications and primarily brought experience of mental health and health and social care services to their involvement. NHS and University respondents pointed to a range of resources including dedicated staff, support and training opportunities they had to support service user and carer involvement (see Appendix 1 – Tables 1 and 2). Service users and carers were clear that support and training needs should be assessed on an individual basis. Although they identified few support and training needs, they were critical of the opportunities available and whether they met their needs.

> *You need to say what training do you want, where do you feel you want it, that's the first question'.* Service user.

Payment for involvement was welcomed by service users and carers as it reinforced their value and expertise. However, although all organisations had funding available, payment was inconsistent.

> *'It's important because it values you as a service user and carer, it also helps people to get back into work'.* Service user.

> *'We're all worried about saying well actually we'd like the money because we're all embarrassed about it'.* Service user.

'The people that I'm there with don't say we'll pay you for that day, they take it for granted that you'll do it for nothing but they're being employed to be there'. Service user.

'We actually have to pay a lot out ourselves anyway like for example if you use your own computer or whatever, it's costing money. Telephone calls cost you money which you don't get reimbursed for'. Service user.

Service user and carer involvement was highly valued by NHS and University staff (see Appendix 1 – Table 3). Evidence of the impact of involvement in terms of achieving changes in practice or service delivery was largely anecdotal. Impacts were identified in the following areas: strategic direction, service delivery, improving the learning experience, and staff recruitment.

'Service user and carer involvement gives a deeper insight into what the 'lived' experience is. Who better to ask about a service than those people who are using it. Who better to ask what works and helps than those people coping with whatever their problems are. It's first hand information from those that really know what it's like 24 hours a day 7 days a week.' NHS Manager.

'Help to develop meaningful services truly based on service users' needs and not others perceptions of need. Keeping the focus real.' NHS Manager.

'Plays a major role in ensuring the Trust provides services that are responsive to the needs and expectations of service users and carers and are therefore likely to be more effective.' NHS manager.

There is a clear need to address the issue of how to measure the impact and effectiveness of service user engagement in education and research. There is, in published and grey literature, a lot of evidence of involvement using different methodologies.

Feedback was not provided to service user and carer participants frequently enough by the NHS and University staff. Few service users and carers were able to identify the outcomes of their involvement that were cited by the staff. This suggests a lack of communication and continuity in terms of maintaining communication to ensure the longer term impacts of involvement were disseminated.

CONCLUSIONS

Service user involvement activity is clearly valued by those involved in mental health research, training and teaching. However, there may be slight differences in understanding and defining meaningful involvement activity between NHS and University organisations and service users and carers. A

wide range of opportunities for involvement exist but there are issues of accessibility and inclusiveness to be addressed. NHS and University staff wanted to involve service users and carers in a meaningful way. To some extent they achieved this and could point to the value of engagement. However, there was no clearly agreed definition of meaningful involvement and no clear inclusive and accessible strategy for engagement. The ad hoc nature of recruitment to activity increases the difficulty of defining meaningful and effective.

There is a clear need to address the issue of how to measure the impact and effectiveness of service user engagement in education and research. The study set out to discover whether it was possible to define meaningful and effective service user and carer involvement. The lack of clear measures for determining the effectiveness of involvement activity, and lack of evidence of impact on practice, meant that this study was unable to clearly define the impact and value of service user and carer involvement in mental health teaching, training and research.

NHS, University and service user and carer respondents agreed that engagement in teaching mental health nursing students, involvement in curriculum development, and collaborating in research activity, were valuable involvement activities. Similarly, they agreed that introducing the service user experience and real lived experiences of mental health were extremely important. Key impacts, from the point of view of the NHS and University respondents, were on the learning experience and on service delivery but these were not evidenced in most cases for the service users and carers in the study

RECOMMENDATIONS FROM THE STUDY

Recommendations include:
1. NHS, University organisations, and service users and carers, should build on the good practice and positive experiences identified in this study specifically in relation to the range of involvement activities offered and expertise of service users and carers.
2. The NHS and Higher Education sector and service users and carers need to work towards a shared understanding of service user and carer involvement activity.
3. Access to involvement activities needs to be more inclusive and transparent and not simply based on personal contact. Understanding the different motivations of each of the stakeholders is also important in recruiting the right people for the task.
4. Although there is a broad range of support and training available, it needs to reflect the needs of the individual and the particular involvement activity or project. Accessibility and timeliness of training opportunities should be reviewed.
5. Systematic reviews of the existing literature on the involvement of service users and carers in health and social care education, training and research

are needed in order to synthesise, appraise and assess the value of the evidence in this topic area. This is of critical importance in defining and recognising effective service user involvement in this areas and providing a benchmark for recognising good practice.

6. Further work to identify relevant outcome measures to determine the impact and effectiveness of service user and carer involvement in health and social care education, training and research needs to take place.

APPENDIX 1

Table 1 – Training opportunities offered by NHS and Universities

SUC specific	Formal	Informal	Research	Other
Developing student case studies Workshops: 'Patients as Trainers'; 'Patient Learning Journey'	Meeting skills Presentation skills Recruitment and Selection Mentoring Access to university training	Open days / taster sessions One-to-one work depending on need	Research skills training, peer review, interview	Induction Self awareness Understanding University process

Table 2 – Support offered by NHS and Universities

Personal support	Practical support	Peer support	Providing links
Mentoring/buddying Ensure SUC well informed, welcomed & engaged Briefing & debriefing Personal communication Openness to enquiries – phone, email, face-to-face Speedy response to enquiries Supervision	Training Dedicated staff member Financially Providing guidelines for involvement Admin/clerical support	Support Group Forum attendance	Links to PALS & PPI team Links to other support network Referral to Occ' Health/mediation services Representation

Table 3 – How service user involvement has added value from the NHS and University perspective

Strategic direction	Service delivery	Improving learning experience	Staff recruitment	Other
Shaped strategic decisions; Service planning; Commenting on policy.	Improving quality of information; Drafting patient information leaflets; Making staff explain their work more clearly; Ensuring services are more responsive; Driving service improvement in developing a new unit;	Reality of experience; Involvement in assessment of students; Leads to re-evaluation of what is important in care delivery; Reinforces the importance of relationships; Keeping academic work real; Increasing students understanding of the user view;	Recruiting staff with right values and attitudes; Identifying poor attitudes;	Bridge gap between NHS, University, student, practice and service user; Partnership; Adding a creative dimension; Research: publications, posters, workshops, presentations, passing on expertise;