

Where Are We Up To With User Involvement In Mental Health services?

A qualitative evaluation study in the Greater Manchester area 2008

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Abstract

This document summarises a qualitative evaluation of service user involvement in Greater Manchester from the views of involved mental health service users, carers and mental health professionals. An exploration of the impact involvement is having on service provision, what it's like for those involved and what are the issues for both groups trying to make it happen. The findings are summarised separately with commentary on the more dominant themes and on those that occur in both sets of interviews.

Context

Service user involvement is widely and consistently recommended in health policy documents, (Hui & Stickley 2007) and has been a legal requirement since the 2001, Health and Social Care Act, along with the supporting policy document, "Strengthening Accountability", (DoH 2003).

In Greater Manchester, anecdotal evidence suggests that there are some good things happening of benefit to mental health services and those users getting involved, but also accounts of where involvement could be better and both workers and users sometimes demoralised by the process. Adequate and appropriate support in the involvement role is an important issue, confirmed by this study and is keenly felt if this is missing, causing people to leave groups or to feel involvement is "tokenistic".

Mentor training for mental health service users to learn the skills needed to support others in an involvement role, was proposed as a useful training intervention by Kate Kennet GMW, NHS Trust, (2007).

"In the North West, there are currently no known initiatives that specifically offer a professional, organised mentoring development opportunity that builds the capacity and capability of all the individuals involved." Yet, "As an approach, mentoring is well established as a development opportunity that can provide direct support, encouragement, increase confidence and enable new skills in the role."

Introduction

Funded by CSIP, and delivered in partnership with blueSCI and Greater Manchester West NHS Foundation Trust, this work is a baseline evaluation to inform the North West Mentor Scheme. There was a need for an exploration of the current picture of service user involvement in one North West area before implementation of the mentoring training courses. The impact of the training and support could then be assessed in terms of any improvements to the effectiveness and overall experience of service user involvement in mental health services. The later research by Sheffield Hallam University will use this work as a scoping evaluation to inform a before and after comparative study.

Aims

To inform the work of, “The Mentoring Scheme for Mental Health Service Users and Carers in Expert Advisory/ Representative Roles.” Through:

- Exploring the perceptions of service users on their involvement role and their impact on services.
- Exploring the perceived success of current service user involvement in Mental Health Services and the factors contributing to that success.
- Examining where involvement roles could be enhanced and where service users experience barriers to further effective involvement.
- Raising the issue of a mentoring role with the research sample and gain initial feedback on this concept.
- Seeking the views of professionals in involvement facilitation roles and issues faced in these roles regarding effective service user involvement.

TERMS - *Definitions for the purposes of this study.*

Service user - somebody who is currently or has recently used primary or secondary care mental health services.

Carer – somebody providing practical or emotional support to a person experiencing emotional or psychological distress.

Involvement – membership of groups or attending meetings for the purpose of providing the user voice to service policy decisions and discussions. (This study does not refer to micro involvement in an individual’s care plans or treatment decisions.)

10 service users interviewed and a further 2 submitted written feedback. All are in representative roles on at least one group or service committee. All are currently in receipt of mental health services. The time spent in their role varies from 2 hours per month up to 25 hours per month. 7 professionals were interviewed. These include service managers, commissioners and a mental health lead. All have some measure of responsibility ensuring user involvement is happening in their area or service.

Method - Qualitative evaluation.

A snowballing sample began with one or two service user and professional contacts. Individuals were then asked to nominate another, who may also have views useful to this evaluation.

One to one semi structured interviews took place with the researcher, people were told the purpose of the work and assured of confidentiality. With participant permission interviews were taped, transcribed and identifying details removed, recordings were then wiped. Interviewing continued until theme saturation had been reached. Anonymous raw data was then sent to the project manager. Transcripts have been analysed on emerging and repeated themes using grounded theory, (Charmaz, 2000), and are summarised in two parts, service user sample group and professional sample group.

Qualitative work has particular value when seeking explore complex issues. (Babbie 2004) In consideration of all of the ways that people can be actively involved in services, all of the personal reasons for being involved and all of the variables that can help or hinder that occupation, qualitative interviews where people had time to consider and explore is the appropriate method for this evaluation.

Using semi structured interview schedules and open questions the participants were invited to explore their experience, ponder and give feedback on the main

involvement issues as they experience them day to day. Their own words and expressions as oppose to any pre set categories that would be unlikely to capture, what it's really like for them. This also worked particularly well when seeking the views of the professionals who appreciated the time in their schedules, to consider this important work, to think it through and reflect in a structured way. Schedules 1 & 2 can be obtained from information@bluesci.org.uk

Summary of Main Findings – service user interviews.

“In hospital you are aware that there is so much that there really isn't right but there's nothing you can do, all your communication is heard and viewed through your diagnosis, so it's pointless. You can either put it all behind you when you get well or have your say and try to reconcile your experience that way.”

Parallel with findings in the literature search, people became involved in services for the following reasons. (Tait & Lester, 2005)

- *To make sense of their own experience.*
- *To improve services for themselves and others.*
- *To ensure the perspective of the service user is heard.*
- *As part of their own recovery journey.*
- *To learn and to gain work experience.*
- *Be part of the culture change in health services.*

Most participants are representing service users generally when they attend meetings, but there is little or no obligation to collect the views of others or to feedback to others on service decisions.

“... I am aware this isn't right, my experience is particular to me. It doesn't follow that I can know what it's like for all service users and I am not charged with seeking the views of others.”

The factors helping people to have a full and effective role in these meetings include:

- *The service user input written into the meeting agenda.*
- *Clear evidence that service user input is making a difference.*
- *Groups achieving a balance between a relaxed and professional atmosphere.*
- *Being paid for involvement work.*
- *An identified person / worker assigned to support service user attendees.*
- *Peer support.*
- *Regular and scheduled feedback.*
- *Assertiveness training.*
- *Reflecting how service user involvement has improved.*
- *Coming from a professional background and understanding the work culture.*
- *Freedom that comes from not being an employee / express views others cannot.*
- *Being confident to express views even if this is to disagree with professionals*

“I’m there for all service users in general and then I represent black service users.”

The sample criteria was service users actively involved in services, hence the feedback on having found at least some groups that work for them to stay involved. These people have, “voted with their feet” when groups don’t work and have joined others, so we are talking to those for whom involvement is working at least on some level.

Reported barriers to a better experience and more effective involvement role:

- *Being the only service user in a group of professionals.*
- *No support or supervision available for doing this work.*
- *Expectations and limits of involvement not addressed.*
- *Being identified as “good” or fitting in and being asked to do too much.*
- *Little or no feedback on role.*
- *Badly managed groups where inappropriate behaviour is not challenged.*

Tokenistic involvement has been experienced by some of the sample and is felt to hold back the potential benefits of involvement working. When it is clear decisions have already been made or people are only treated well when they are needed to “rubber stamp” a new policy or decision.

“When it’s important to get you on side you are made welcome and spoken to. It’s become pretty obvious it’s when you are useful rather than the fact we are full members of the group.”

“It’s like there’s not enough attention paid to people’s expectations or their needs or why they’re even there. Get them in a group and that’s service user involvement covered.”

Almost all of the sample group intend to stay involved in mental health services and feel their input will be relevant for the foreseeable future. This is reportedly about the amount of work still to be done, how slow the service changes are felt to be and to fight stigma in society as a whole.

“There’s too much to do and the changes are slow. There are mistakes being made now that will mean more people in crisis.”

“I’ll leave when we live in a world where mental health problems are not stigmatised.”

Without exception the sample group said they would support somebody else to do a similar role and when asked what advice they would give to somebody new, the need for support is the dominant theme.

When asked to suggest better ways to do involvement in mental health services:

- *Positive recruitment and paid jobs for users within the services*
- *Service user led research groups*
- *Payments made simpler and fair pay for involvement.*
- *A peer support service.*
- *More outreach to groups who don't attend meetings.*
- *An induction and training programme for all those involved.*
- *Involvement in staff training programmes.*

“Yes, I think that’s probably the way forward. Mentoring it’s called and I could do that role and pass on my skills. Lots of people who may be good at involvement would find it hard to start without support, it’s a big ask if your confidence has been knocked by illness.”

Summary of Main Findings - professional interviews

“... the voice of service users is to be proud of, encouraged and enabled.”

In contrast to the literature search on this subject, (Stickley, 2006) & (Robert et al. 2002), where professional resistance is found to the idea of “users as experts”, the professionals interviewed in this evaluation were fully signed up to involvement. They were found to be more than positive when asked about the political direction, gains to services, benefits to individuals, power sharing and culture change in mental health service provision.

The positives of service user involvement from the professional view:

- *Making services more appropriate and effective/ service improves.*
- *Finding out what new services are needed.*
- *New services set up and commissioned based on service user input.*
- *Service users bring expertise and healthy challenge to decision making groups.*
- *Professionals more accountable to service users and welcome this.*
- *Service users on staff recruitment panels / more appropriate appointments.*
- *Users often ahead of staff in the modernisation and recovery working agenda.*
- *Involvement process part of service user recovery.*
- *User Focussed Monitoring / evidence and wider representation.*
- *Stronger user groups with ongoing funding.*
- *Recruitment of service user development worker, (some areas).*

“... how closely linked the service users are to the whole direction of change, they are miles ahead of the staff on this.”

Reported barriers to more effective service user involvement:

- *Not having enough time to focus on service user involvement.*
- *Not enough time to support people properly.*
- *Little or no budget for this work, or for service user payments.*
- *Little or no training available for service users.*
- *Not part of official job description or responsibility.*
- *Little or no specific support, guidance or supervision for involvement work.*
- *Difficult to balance service user expectations with national service directives.*
- *Representation concerns.*

“... the lack of really good guidance from above and the time spend searching for guidance against other things to be done.”

“I tried to support people where I could, but my time was so limited. Others probably came and left without much support.”

From these findings, it would appear that professionals working in service user involvement have this important task as an “add on”, to their main responsibilities. Areas who have managed to find the money for a service user development worker or have resource to a strong and independent service user group fair better and clearly good practice is happening, changes and improvements to services are being made. Aware they have too little time and money is a major finding from this sample group and this will impact on support and development time, training for service users, adequate preparation and information sharing. The potential of service user involvement is therefore limited and the professional interviewees report that good outcomes are ***“too patchy”***.

Representation as an issue is well discussed in the wider literature and occurs again in this work. The professionals sense that access to the service user voice is partial and does not include all relevant groups. There is a well worn cliché ***“always the same people”*** and findings in this work question where this may be compounded by practice starved of time and investment.

When asked if they would seek a turnover of involved service users responses were largely in line with, ***“I would like to rather than do... It would be good to get the views of those who don’t speak out much. Again this goes back to development and support time.”***

A closely related issue also discussed in the user interviews, is the service user who fits in easily due to their professional background, needing no training and less support. These service users are often asked to do too much, potentially making them, ***“always the same people”***.

“... It’s about those with a similar background to the professionals and there’s a risk of taking advantage of them because they fit in so well and easily. I would not want to be elitist, but it is a problem.”

The professional views on how to improve the effectiveness of service user involvement:

- *Raise the profile of service user involvement.*
- *Clear commitment from senior executives signalling the importance of this work.*
- *Mainstream and continued funding, including money to pay service users.*
- *A service user development worker for each area.*
- *Properly facilitated peer support / mentoring.*
- *Training, skills and development audit for all groups.*
- *Regular training available to enhance involvement working.*
- *Service user research groups charged with monitoring current services.*
- *More independent service user organisations.*
- *Groups having more say in how they contribute.*
- *Wider representation.*

Conclusions-

Whilst a relatively small and local study, many of the findings in this evaluation are aligned with larger research around this subject area. This suggests some issues in mental health service user involvement in Greater Manchester go beyond the local and are more likely National issues for mental health services.

Service user involvement in mental health can work for services and for those actively involved. New services have been commissioned in Greater Manchester based on the user input at planning and commissioning meetings. A few of these services have had user involvement in every stage of the process and include users on their management teams. People are managing to find fulfilling

involvement roles and have shared evidence of where their input has made a real difference for themselves and others.

Particular to this study is the suggestion that professional sign up, responsiveness and power sharing has improved in recent years and this is from an analysis of both groups of interviewees. That said, the service users and professionals all report that things could be much better and good practice much more consistent. A lot more support, feedback, training and paid jobs would improve things say the service users.

Time, money and good guidance would improve things say the professionals and they are keenly aware of how their issues compound the lack of support and development issues that the involved users face.

Also particular to this study is the exploration by both interview groups of service users with a professional background fitting in easily to the work culture and needing less support where little or at best inconsistent support is available. And there are the contrasting opinions on the issue of tokenistic involvement, the service users report that this can still be a problem, the professionals in this study believe this is a thing of the past. Do the professionals perceptions of tokenism differ from those on the receiving end?

Considering all of the positive reasons people get involved in services; *to reconcile their experience, improve provision, as part of their recovery...*, set against the professionals limited time for support or training, it would seem positive that more people gain access to support from those who are managing to make involvement work for them. Good quality and supported mentoring relationships is one proposal to aid this process.

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