Audit of User Involvement Service

Standards in Rehabilitation Services

(Formerly known as RCCS)

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Introduction

Health policy guidelines state that people who use mental health services should be involved in the planning and delivery of care that they receive (DoH 1999). Whilst services are starting to address these national directives, it is less clear what is meant by involvement, how this may occur and most significantly, why involvement is so important. This paper addresses some of these questions by reporting a collaborative action orientated audit examining the extent to which an adult mental health service implemented local service standards designed to promote the involvement of users** of the service. What users would like from services has been reported elsewhere (Gell, 1997, Rogers, 1993), the point now is to change services. This paper examines the extent services have introduced changes promoting user involvement.

** The term users, refers to people who either, have used or continue to use mental health services. The term is used throughout the paper as a mark of respect for people who have personal and intimate experiences and knowledge of services. The paper refers to users in a collective sense but fundamentally recognises and values all experiences are individual and unique.
This section considers, how user involvement has been defined, why user involvement is so important and finally expresses some caveats about the limitations of user involvement to date.

**What is user involvement?**

Involving people who receive support from mental health services in their care occurs in various capacities, structures and remits. There are good practice guides developed by both professionals and people who use or have used services (Williams and Lindley, 1996; Lindow, 1996; Morris, 1996). The socio-political context of user involvement and the history of the user movement are summarised by Pilgrim (1998) and Campbell (1996) respectively. Davis et al (2001) identified many examples of involvement, including staff recruitment, training, research and employment. Peck (2002) developed a matrix to identify how and in what way users were involved. The matrix contrasted concepts of user involvement such as, recipients of communication, subject of consultation and agent in control with levels of interaction, such as, interaction between service users, between users and professionals, management of local services and planning of overall services. Hickey (1998) identified a participation continuum which sequentially included: information/explanation, consultation, partnership and user-control, the former two, Hickey describes as a “consumerist approach” and the latter two refer to active citizenship through a process of democratisation. There are many reasons why user involvement should be established, from the more conservative position such as eliciting users’ views (Bhui, 1998; Ebrahim, 1999) to more progressive positions of users planning and delivering services through active citizenship (Barnes and Shardlow, 1997).
Why user involvement is so important

This paper suggests it is essential for people who use mental health services to be more involved in services, in practice and theory. It is recognised that our current understanding of psychological distress is partial and limited (Smail, 1993). The inclusion of users’ experiences and knowledge will elaborate our existing understanding of distress and user involvement is one way of achieving this. May (2001) advocates, “user involvement in service provision is an opportunity to contribute to a much-needed change in the value ascribed to their (user’s) knowledge of confusion, distress, social exclusion and what helps recovery”. May continues, to avoid the “us and them” culture, training for mental health professionals should value the personal narrative, where personal experience is not seen as subjective and irrelevant but a valuable evidence base. A comprehensive framework for practice in mental health services will only be achieved by respecting and including knowledge that users have of services and, has hitherto been quietened and subjugated to the dominant psychiatric discourse. Harper (2002) advocates moving away from the “tyranny of expert knowledge” whereby professionals protectively control agendas, preferring to move towards a new inclusive body of knowledge. Many positive developments are described when users of services are involved in the training of mental health workers. Harper (2003) reports the benefits from inviting users to contribute to Clinical psychology training, including, rethinking psychological theories, being challenged, affording respect and maintaining an openness and liveliness in discussion. A similar process of inclusion is necessary for the future development of Social work theory, argues Beresford (2000).

Current limitations to user involvement

There are many accounts of user’s and survivor’s experiences of distress (Read and Reynolds, 1996). Wallcraft and Michaelson (2001) propose developing a survivor discourse to replace the ‘psychopathology’ of breakdown and crisis, with a discourse which is less stigmatising, less dismissive, more meaningful and purposeful. Campbell (2001) points out,
“social inclusion needs to be based on a positive vision, a belief that the newly included will bring something valuable, not that if we watch them (users) closely enough then they probably won’t mess up.” Campbell adds, “the rhetoric of partnership, implying as it does a large measure of equality and a close identity of interests and objectives is usually much more comfortable for those with the power, those handing out the invitations.” Campbell’s warning is a sobering caution that user involvement may be tokenistic, ill-considered and poorly implemented. Bowl (1996) discovered that there was confusion about the purpose and meaning of user involvement in Social services departments. Despite the fine words, Bowl found little evidence of power sharing and limited commitment to the necessary resources to promote partnership involvement. Staff were also found to be resistant to user involvement in the selection of staff. This led Bowl to conclude that staff training was necessary for the successful implementation of user involvement. Staff attitudes are frequently cited as significant to the process of user involvement (Williams op cit, Davis, op cit). Pilgrim (op cit) also emphasises the importance of securing adequate resources to develop user involvement, arguing that, “just as the status quo of mental health services cannot be maintained without finance, any change in such services would also require stable financial backing.” Pilgrim details some constructive developments in local services but warns, most investment remains within bricks and mortar, the medical discourse in mental health remains as powerful and current policies such as the supervision register mark a return of policy on surveillance and control. Newnes (2001) also cautions, despite some encouraging signs supporting users to have a voice, other user groups have faltered and user participation may not be as widely dispersed as it would be hoped. Newnes continues, user’s opinions are often subjugated and the dominant psychiatric discourse prevails.
User involvement and research

People who use or have used mental health services are undertaking research in various capacities, as research partners (Ramon, 2001) and independent researchers (Rose, 1999. Morrison, 2000. Castillo, 2000). Faulkener (1998) notes that users have every right to ask the questions in research. Described as emancipatory research, Faulkener advocates user involvement is a process aimed at users becoming “active agents in the research process and away from passive objects of study.” A local group in Nottingham of independent service user researchers, Service users monitoring services (SUMS) worked collaboratively with a Clinical Psychologist (first author) on the following audit project. This initiative is one of several research projects undertaken by SUMS (for a full account see, SUMS, 2000).

Aims of the study

This study is informed by critical psychology (Prilleltensky, I. 2002) and community psychology (Bostock, J. 1998). Both advocate, amongst other things, promoting collaborations linking theory with action, addressing issues of power and considering ways of devolving professional power, and challenging stigma and pathologies perpetuated within systems. Community psychology is interested in addressing sources of oppression and working towards transformational change towards a more just society. It espouses primary values of caring, compassion and health. Transformational change towards a more just society may occur when second order change values including, self-determination, participation and human diversity are embraced. It is proposed that user involvement in services is one way of introducing change within mental health services. This paper will examine to what extent change is possible in relation to primary and second order change.

The aims of the study are to, audit service standards supporting user involvement, evaluate service structures and staff attitudes to enable and facilitate further involvement of people who use mental health services.
Methodology

Procedure
In March 2000 the Rehabilitation and Community Care Service, Nottinghamshire Healthcare Trust including residential, day care and community teams, a total of 16 teams, introduced service standards related to the current practice and future developments of involving people who use the service (see Appendix A). The standards for user involvement, along with a summary of current practice in the Rehabilitation service and guidelines for developing good practice were documented in the booklet, User Involvement: current practice and future developments (Diamond & Butler, 2000) and circulated to all teams. All teams were asked to work to these standards. The standards were developed by a group comprising, volunteers, advocates, user development workers and members of staff. The standards addressed the issues highlighted in the introduction to this paper and included, user involvement in the following areas: staff recruitment, care planning, self-assessment, evaluation of services, staff training, organisation and planning of services and advocacy services. Eighteen months later, the Clinical Audit Department funded a project to ascertain how effective the service standards were. The funding was principally for the employment of members of the SUMS group. The audit was co-designed by the authors. Following completion of the analysis of the data, members of the SUMS group provided feedback to staff groups.

Participants
All teams in the Rehabilitation service were invited to take part, six residential, three day care and seven community teams, a total of sixteen teams. Pairs of interviewers from the SUMS group interviewed two members of staff from each team independently to ensure a representation of views from each team. In all cases this included a Team Leader/Deputy Team Leader and member of staff from the respective team.
**Measures**

The audit questionnaire was co-designed by the authors. In order to audit the standards, the questions focused specifically on the original set of eleven service standards (see Appendix B for questionnaire). The design group were keen, not only to include questions that would address service standards, but also to establish why it may not have been possible to implement some of the standards and what improvements could be made to address any shortfall.

**Results**

The response rate was 84%, in total, 27 interviews were undertaken. The non-responses were one community and one residential team. Every effort was made by the SUMS group to organise interviews with all teams. There were two interviews with each team, Quantitative data is presented as total percentages for the service with summed results for residential, day care and community services. Further detailed analysis of residential, day care and community services is provided in Appendix C).
Table 1 and Table 2 shows staff responses to the Service standards

**TABLE 1**

<table>
<thead>
<tr>
<th>USER INVOLVEMENT SERVICE STANDARDS</th>
<th>Yes</th>
<th>No</th>
<th>Sometimes/ Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are there regular meetings for people who use your service ?</td>
<td>70%</td>
<td>30%</td>
<td></td>
</tr>
<tr>
<td>Are people who use your service or advocates actively involved in staff recruitment, such as short listing, interviewing and appointment ?</td>
<td>78%</td>
<td>22%</td>
<td></td>
</tr>
<tr>
<td>At regular staff meetings, is there a standing agenda item addressing peoples’ views who use your service ?</td>
<td>48%</td>
<td>52%</td>
<td></td>
</tr>
<tr>
<td>Within the last year, has the team carried out a survey asking people their views about the service they receive?</td>
<td>59%</td>
<td>33%</td>
<td>8%</td>
</tr>
<tr>
<td>When producing a care plan, is the Meeting Your Needs: self assessment form included?</td>
<td>55%</td>
<td>37%</td>
<td>8%</td>
</tr>
<tr>
<td>During staff induction training, does the service include the booklet, User Involvement: current practices and future developments?</td>
<td>26%</td>
<td>59%</td>
<td>15%</td>
</tr>
</tbody>
</table>
TABLE 2

<table>
<thead>
<tr>
<th>USER INVOLVEMENT SERVICE STANDARDS</th>
<th>None of the time</th>
<th>Occasionally</th>
<th>Often/frequent</th>
<th>All of the time</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are people who use your service or advocates involved in the evaluation of your service?</td>
<td>15%</td>
<td>18%</td>
<td>30%</td>
<td>11%</td>
<td>26%</td>
</tr>
<tr>
<td>Are people who use your service or advocates involved in staff training?</td>
<td>59%</td>
<td>33%</td>
<td>4%</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>Are there opportunities in your service for people who use your service or advocates to contribute to the organisation and planning of the service?</td>
<td>0</td>
<td>26%</td>
<td>37%</td>
<td>37%</td>
<td></td>
</tr>
<tr>
<td>What links do the team have with advocacy services?</td>
<td>11%</td>
<td>63%</td>
<td>19%</td>
<td>7%</td>
<td></td>
</tr>
</tbody>
</table>

One further service standard question was, ‘what efforts were made by the team to ensure that people who use your service are actively involved in their own care plan?’. The majority of responses focused on the care plan and its composition, for example, emphasising one to one co-operation and collaboration before the written plan was formulated with self assessment and the strengths approach as central considerations in the process. There was also recognition of the need for staff to relinquish control whilst concomitantly encouraging people who use services to take more control and influence.

There were two further follow up questions to those asked in tables 1 and 2 which related to, ‘if regular meetings were arranged for people who use services, how were the meetings facilitated?’ Secondly, ‘if the self-assessment form, ‘Meeting Your Needs’, was used in care
planning, how useful was it?’ The data show, 84% of user’s meetings were staff facilitated, 10.5% external advocate facilitated and 5.5% neither. Regarding the usefulness of the self-assessment form; 71% of staff who used the form found it useful, 5% did not and 24% reported, not appropriate, because their service does not organise care plans.

Seventy percent of the service was able to organise meetings for people who use the service, the areas where this was not possible were the community services. Seventy eight percent of staff considered people who use mental health services were involved with staff recruitment. There was some variation within, short listing, interviewing and appointing. Some users were not involved in the short listing procedure. Reasons given for this referred to confidentiality. The most successful services involving users in recruitment were Day services where training and support to users involved in staff recruitment had been provided recently. Less than 50% of services had a standing agenda item at their regular weekly team meeting addressing user’s views. In Day Care and Community services this dropped to below 33%. The results showing how involved people are in the evaluation of services are spread from 15% none of the time to 11% all of the time, with 30% citing users are often involved. Most of the examples cited tended to refer to informal opportunities and lacked specific details. Similarly, 59% of services did not have any people who use services involved in staff training. Thirty three percent had occasional involvement. Where this occurred it tended to be through user development worker posts or presentations given by people who use services. There were higher responses for the involvement of users in planning services. Thirty seven percent of staff reported involvement all of the time with similar ratings for often and occasional involvement. The level of organisational planning tended to be within specific teams and units and involved practical measures such as, choice of internal and immediate surrounding environments, user-run café, development of outreach services.
There is an independent advocacy service in the local area, staff were asked what level of involvement they had with advocacy services. Sixty three percent had occasional contact, 19% frequent, 11% none and 7% constant. The more regular take up of contact with advocacy services was in the Community and Day Care services. Residential services had less contact. When asked if they had undertaken a survey of people’s views who use their service, 59% of staff responded they had and 33% had not. This finding was reasonably consistent across all three parts of the rehabilitation service. When preparing for a care plan, a self-assessment form should be included, 55% of staff stated this was the case. This figure rose to 60% and 73% for Residential and Community services respectively where most care planning is undertaken. Finally, staff were asked whether or not their staff induction training included the Rehabilitation service’s user involvement guide, 26% reported they were, 59% were not and 16% did not know.

Another objective of the study was to elicit how improvements could be made to promote the involvement of people who use services. Staff suggested increases in independent advocacy services and support for the involvement of organisations that are independent from the Rehabilitation service. Similarly, an increased role for groups like SUMS to undertake independent audits and evaluations. Staff suggested the Trust organisation had a responsibility to provide structures, processes and training which encapsulates the values of increasing the involvement of people who use services. Currently, there are a few user development worker posts in the service, staff recommended additional posts. Staff highlighted the importance of being creative and imaginative in their work and looking beyond a dominant medical approach to mental health, this involves minimising jargon and adopting a flexible approach to encouraging and learning from users. Finally, staff considered the development of sustainable therapeutic relationships as a cornerstone to valuing and respecting user’s involvement in services.
The majority of staff responses were positive and constructive. In some instances, where there were shortfalls in the standards, staff acknowledged limitations and agreed to try and address the shortfall. A few staff comments implied reservations and doubts about further user involvement, such as, “users not always interested due to illness and severe problems”, “problems motivating clients”, “users as trainers is difficult as clients are often in crisis”, and "staff are aware of client’s illness, therefore, user talks not necessary.”

**Discussion**

User involvement in the rehabilitation service is more established in some areas than others. This section considers the following areas; established practice, the importance of reflexivity, the need for staff training, the dangers of resting on laurels and finally suggests ways forward. Staff supported the aims and values of the audit and acknowledged that whilst there were areas of good practice, more could be done.

**Established ways**

There appears to be relatively high levels of involvement in the recruitment of staff. This is an area of user involvement introduced some years ago. On-going training and support for potential users involved in staff recruitment is essential. There remains some related issues to address such as payment rates during the process but this is well established. Another area of established practice includes meetings for people who use services, again this is a high response but it should be noted that the high level refers to residential and day care units, ie, bricks and mortar settings. It was a much lower rate for user’s meetings in community services, where it was reported it was difficult to invite people together. Furthermore, it should be noted that most user’s meetings were facilitated by members of staff, only 10.5% were advocate supported and 5.5% were neither staff nor advocate supported. There is evidence of established practice involving users in some aspects of their care, however, it is important to ensure further developments by providing both structures
and resources placed at the disposal of users. For example, more independent advocacy would promote this.

**Reflexive practice**

The audit suggests that there is a continual need to support and promote the values of user involvement whilst it becomes engrained in good practice. Staff teams acknowledged that there should be a regular weekly standing item at their team meetings addressing user’s views. Obviously, there is a danger that this could be tokenistic, future audits could evaluate the purpose and outcomes of this inclusion. Several studies have shown the importance of staff attitudes and how they can obstruct partnership working between users and services. It is suggested that the inclusion of user’s views at regular team meetings is better present than absent, thus reminding staff of the position and views of users. Reflexive practice would be enhanced by ensuring surveys were conducted that elicited user’s views, currently this involves 59% of teams. In the past this standard received a higher completion rate, the current level may be due to some confusion by a similar Trust initiative that was started but not continued.

**Staff training**

More recent developments such as user involvement in staff training is less well supported. Some staff were unclear what this entailed and others unsure where and how to go about it. Staff attitudes and sympathies towards new ways of working are instrumental in effecting or resisting change. Whilst there is little evidence to imply staff are opposed to the initiative, the result suggests there is much work to be done to establish a training and development role for users. There are support and training issues for both people who use services to be encouraged to get involved and also for staff to question some of their existing training. This development should not be ad hoc, nor dependent upon the persuasion of a particular member of staff to support it. User involvement should become a core element in staff
training and development, it is key to embracing an elaborated understanding of distress. It has been shown that our current knowledge of mental health difficulties is partial and limited, leaving gaps in our knowledge. It is crucial to further learning in this area to respect and value the knowledge and experiences of people who have used services. Staff recognised that this area should be promoted by the Trust's training and development department. The introduction of the self-assessment form during all therapeutic work and the inclusion of user involvement standards during all staff inductions are two ways of adding procedural structures to consolidate user involvement. Currently staff response rates to the latter two standards were relatively low. It should be noted, however, that when the self-assessment form was used during care planning, over 70% of staff found it useful.

**Not resting on laurels**

Links with the local independent advocacy service were limited. Despite frequent requests, demands on the advocacy service across Nottingham allowed for only minimal input to the teams in this study. Staff recognised this shortfall and requested further input from external advocacy services, an increase of User development worker posts and more support for the research role of SUMS. Staff also reported the benefits of an independent user-researcher group such as SUMS particularly when responding to the service standard, user involvement in the evaluation of services. Responses to user involvement in evaluation of services indicate a spread across the range and with the exception of several audits undertaken by SUMS, there were few substantial examples given. Staff commented that users were asked their views of what they thought about aspects of care, however, on some occasions, this was not formally undertaken and would benefit from formalised audits linking feedback to actions. Over one quarter of staff did not know whether or not anything was happening. This is an area that requires further development. There were more examples cited referring to user involvement in organisation and planning of services, these include, user-run café, development of residential-outreach services, need for health check-ups and development of
living environments in residential areas. This result suggests that at least in some areas the views of users of services are respected and acted upon.

A collaborative venture

This study was a collaborative project between a user-researcher group and a member of staff. SUMS members reported, feeling “nervous” about interviewing staff, but soon realised staff could also be nervous. Some interviewers knew staff from the past, when they were unwell, therefore, had concerns that staff may try to nurse them, this was not found to be the case. The SUMS group wondered whether, because they were users of services, staff did, on occasions report answers that would be favourable to the desired response. This was speculated because, despite being asked to provide specific examples of user involvement to illustrate responses, answers were not always elaborated. SUMS had undertaken previous surveys interviewing users of services, whilst it was reported that the latter were “easier to talk with”, there was much satisfaction at the successful conclusion of the present audit. There are further plans to undertake similar follow up projects. SUMS members received training and development in research methods prior to this audit. The research group would acknowledge the support offered to one another throughout the project and the importance of keeping open communication and critical reflection.

It is recognised that this study focused solely on the service and staff’s opinions and did not address the views of user’s of services. The aim of this paper was to evaluate what services were doing about user involvement, as such, the standards established are the responsibility of services, it is only staff, with regard to some standards, that are able to respond. A future survey including the views and experiences of people who use services would strengthen these results. It is also recognised that there are limitations to self -reports related to the quality of services, there were occasions when positive responses were not substantiated
with detailed examples of practice. It is recommended that a follow up audit be undertaken to evaluate the outcomes and changes recommended by the present study.

**Recommendations**

The audit makes the following recommendations:

- More resources for advocacy services
- More training, support and resources for user involvement
- Organisational responsibility to incorporate user involvement at all levels
- A statutory role for the organisational training & development department
- Extend user development worker posts
- Further contracts for independent user-researcher groups
- Develop sustainable therapeutic relationships with meaningful dialogue which recognises issues of power and minimises jargon
- Similar user involvement standards to be introduced throughout Adult Mental Health Services, Nottingham

**Addendum**

Since the writing of this paper, the SUMS group have renamed and are now known as Making Waves.
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