

WHO-EC Partnership Project on User Empowerment in Mental Health

Quality Assurance / Monitoring of Mental Health
Services by Service Users and Carers

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Empowerment is not a destination, but a journey

From *User Empowerment in Mental Health: a statement by the WHO Regional Office for Europe* WHO/EC (2010)

It's common sense, really. Involve the customers in the decision-making, and you're going to get a better product.

Dr Richard Bentall in an interview to the *New York Times* (November 30th 2009)

if the evaluation of services [is] genuinely to reflect the concerns and views of the people who use them rather than those of providers, then users should lead the process at every stage: from the questions asked, through the collection, analysis and interpretation of data to the final reporting of the results and development of recommendations for change.

From *A Guide to User Focussed Monitoring* (2007) Sainsbury Centre for Mental Health

Statement of topic

This paper summarises what is currently known about the empowerment of people with mental health problems and their family/carers in relation to the quality assurance and monitoring of mental health services. It includes evidence from the literature about what works, and implications and options for policy makers. It concludes with a number of practical recommendations for policy makers, service providers and others.

1. Background to the issue

The empowerment of mental health service users and carers is one of four key priorities for WHO in Europe. The recent WHO statement defines empowerment as:

the level of choice, influence and control that users of mental health services can exercise over events in their lives (WHO, 2010).

Throughout Europe, mental health service users face social exclusion and discrimination, often lacking information, choice and control when in contact with mental health services. Their friends and families are also often excluded from decision-making in mental health.

WHO (2008) collected baseline data in 42 countries from the European Region, finding little evidence of systematic, meaningful service user or carer involvement in quality assuring services. Muijen commented:

A particularly important indicator of empowerment is for us whether users and carers are involved as full members in the external inspection of services ... Remarkably few countries confirm that they do so, despite positive experiences in places who have tried this. (Reported in the minutes of the Lille seminar 2008)

Yet such involvement leads to evaluations which are more relevant to people's needs and concerns. Further benefits include developing more relevant outcome indicators, improving the quality of information obtained from service recipients (who often speak more freely to peer interviewers), and suggesting practical change strategies to improve services (Davidson et al 2009). There is evidence that involvement in quality assurance enhances peoples' skills, confidence and sense of worth (Kotecha et al 2007).

WHO are currently producing guidance standards for European countries for the empowerment of service users and carers (Crepaz-Keay 2010). These include standards for service user and carer involvement in inspecting and monitoring services such as:

- Are [service users and carers] engaged in national policy making and its implementation, research, training, monitoring and inspection?
- Is there a statutory right for service users to be involved in local implementation and monitoring of services?
- Offer people who use services the chance to be partners or to be involved in all stages and levels of running, planning, delivering and evaluating services

2. Policy implications and policy options

Creating a national policy strategy to sustain involvement

Currently only Holland and the UK have legislative requirements for engaging patients and the public in healthcare policy. Other European countries use local democratic mechanisms, plus patients' rights and complaint systems. Effective involvement needs a strategy that goes beyond simply electing lay representatives to boards and committees since many people with health problems feel unable to stand for election, or may drop out from regular participation once elected (Tritter & McCallum 2006).

Thinking about involvement

Concepts of involvement have been much influenced by Arnstein's ladder of citizen participation (1969). However, this may no longer fit the complexity of real life situations in differing political and social cultures:

A linear, hierarchical model of involvement – Arnstein's ladder – fails to capture the dynamic and evolutionary nature of user involvement...user involvement requires that the structure and process be dynamic and negotiated by users themselves. (Tritter & McCallum 2006 p.166)

Policy makers need to work with diverse individuals and groups at local, organisational and national levels in ways which fit their country's situation, as well as taking on board essential principles and values of empowerment. Involvement systems should be flexible enough to evolve towards equal partnership with stakeholders where this is not yet happening.

Methods of involvement

Several European countries have developed methods which have been used locally and nationally to engage service users and carers in the quality assurance and monitoring of services. These range from consultation exercises and surveys, to service users and carers participating as full members of service inspection teams, to service user-led evaluation and monitoring of services (see Appendix).

Consultation and survey methods

Surveys, focus groups and other kinds of consultation can provide an opportunity for large numbers of service users and family members to give their views. If the same exercise is repeated, changes over time can be monitored. This method works best when service users and family members are actively involved in developing and carrying out the consultation to ensure questions are relevant.

Involvement as partners in service inspection teams

Service users and family members can be invited and trained to take part in existing service inspection teams, with the same status as other inspectors. This can work well

and may not require additional funding. One disadvantage may be that working with a standard inspection system does not give lay inspectors an opportunity to represent their own views or those of their peers.

Other methods include 'mystery shopping', which is a form of market research. The principles have been adapted for quality assurance of mental health services. Service users may be asked to give anonymous feedback about services they use (Heingartner 2009).

User focussed monitoring

In this method, service users are trained to conduct interviews, focus groups or surveys with other service users on their experiences and views of mental health services. The researchers are typically drawn from the service being evaluated, and help in generating relevant questions for their peer group. Conferences are then held between service providers and service user representatives to discuss ways of strengthening and improving service delivery. This method draws on the experiences and perspectives of those using services, and builds service users' confidence and capacity. As with conventional surveys, repeated cycles of research and feedback lead to service improvements (User Interviewing User 2006; Kotecha et al 2007).

3. Conclusions and recommendations for action

European member states have different legislative frameworks for lay involvement and have reached different stages in this work. We recommend that nations develop a strategy to fit their starting point. This could mean beginning with consultative approaches and building towards partnership models and service user focussed monitoring. Those countries which already have some service user-led work could further develop and widen this.

We believe that the following recommendations are basic essentials for effective service user and carer involvement in quality assurance and monitoring.

1. Work towards national frameworks to support involvement.

Involvement in quality assurance and monitoring works best when supported by a co-ordinated and funded national policy structure, backed by legislation (Tritter & McCallum 2006). Where this does not exist, service users, carers and service providers need to lobby for change.

2. Ensure quality assurance and monitoring leads to service improvement

Ideally, there should be continuous cycles of monitoring, evaluation and development of services.

3. Conduct quality assurance from service user' and carer' perspectives

Assessments that involve service users and carers should address the factors that are important from their perspective (Campbell 2009).

4. Apply good practice principles

There are numerous examples of good practice principles for user involvement that apply equally to involvement in monitoring services (see for example Schrank & Wallcraft 2009). Such principles include:

- Ensure adequate funding for involvement
- Provide training and support for all stakeholders
- Ensure clarity and transparency regarding the purpose of evaluations.

5. Understand and adopt core principles

There are a number of core principles that all stakeholders (policy makers, service providers, service users and carers) must understand and sign up to for service user/carer involvement in evaluation to work. These include:

- Only service users can represent service users, and only carers can represent carers.
- Service users and their families are the best people to comment on service quality.
- Service users' and carers' views and experiences must be valued and seen as valid and credible.
- The view of of service users or carers should not be invalidated by saying they are 'unrepresentative'.
- Service user/carer involvement in evaluations must not lead to reprisals.

6. Capacity build amongst service user and carer organisations across Europe

Service user and carer movements have developed at different rates across Europe. There is always a need for investment in the infrastructure, capability and networking opportunities for service user and carer groups to do this work.

7. Win hearts and minds

For involvement to be effective, everyone needs to believe in its value, and trust should be built between staff and service user and carer organisations. Involvement works best if there is someone to champion it, preferably at a high level in the relevant statutory body.

8. Evaluate involvement of service users and carers

The systems and methods chosen for service user/carer involvement in evaluations themselves need monitoring in order to develop best practice and improve effectiveness.

9. Be innovative

Although we recommend the above as essential actions, we also believe that stakeholders must be flexible and innovative in thinking about user and carer evaluations of services, ensuring that any evaluations are sensitive to local context.

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