Involving users in the delivery and evaluation of mental health services: a systematic review

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Authors' objectives
To identify evidence from comparative studies on the effects of involving users in the delivery and evaluation of mental health services.

Searching
The following databases were searched between January 1966 and October 2001 for references in English: MEDLINE, EMBASE, CINAHL, PsycINFO, HealthSTAR, the Cochrane Controlled Trials Register, ISI Web of Science, HMIC, and databases on BIDS (the search terms used in MEDLINE were presented in the published paper). The authors also wrote to experts and organisations that had an interest involving health care users, and handsearched collections held by the Health Sciences Library of the University of Leeds. The references of all retrieved articles were also examined.

Study selection

Study designs of evaluations included in the review
The authors did not define any a priori inclusion or exclusion criteria relating to the study design. The included studies were randomised controlled trials (RCTs) or comparative studies.

Specific interventions included in the review
The intervention of interest included the involvement of users in the delivery or evaluation of mental health services. More specifically, evaluations of the impact of research on services if users had an active role in the design or in collecting data, and studies about users who delivered services by training mental health professionals. Also considered for inclusion were studies looking at service delivery involving users in partnership with others if the services were: integrated by health professionals and users working together in a team; cross-consultation; or recruitment, training, supervision, or payment of users by health care providers. Studies that only dealt with the following criteria were excluded: learning disabilities; involvement in decisions about a user’s own treatment; the provision of information to users; user satisfaction surveys that were researched by the provider (which do not require users' partnership); general health services not specifically aimed at mentally ill people; forensic services; services for mentally ill people that are not health related, such as housing or vocational rehabilitation; services with no contact with professionals or which could not be run by professionals operating outside of the mental health system.

The users involved in the included studies were current or former users of mental health services who had had serious psychiatric illness (most commonly schizophrenia or bipolar disorder) and had been hospitalised. Employees who were or who had been users of mental health services and interviewers had similar disorders to their clients. All the interviewers and employees that were users had received training. Half of the included studies focused on involving users as service providers, mainly working as case managers in services for clients with severe mental illness.

Participants included in the review
The participants were clients (recipients of services in which users are employed) of mental health services.

Outcomes assessed in the review
The authors appear to have been interested in any reported positive or negative effect, but no a priori inclusion criteria relating to the outcome measures were reported. The included studies reported a variety of types of outcomes: satisfaction with personal circumstances or services; income; level of functioning; attitude to drug compliance; social contacts; symptoms; hospitalisation (and time to hospitalisation); attitude of staff towards users; arrest; homelessness; quality of life; family burden; crises events or use of crises services; social support; drug use; and relationship between client and case manager.

How were decisions on the relevance of primary studies made?
The papers were checked for the inclusion and exclusion criteria by both authors independently.
Assessment of study quality
The following criteria were considered when assessing the quality of the included studies: method of randomisation, evidence of blinding during data collection, and an intention-to-treat analysis. The authors do not state how the papers were assessed for quality, or how many of the reviewers performed the quality assessment.

Data extraction
The following data were extracted independently by both authors using a standardised form: mechanism of involving users (including support available); numbers of users involved and diagnoses; service or setting of involvement; study design (including numbers in comparison groups); all measures of the process of involving users; all measures of outcomes for employees who were or who had been users and their clients.

Methods of synthesis
How were the studies combined?
The studies were combined in a narrative summary.

How were differences between studies investigated?
Differences between the studies were discussed in the text. The studies were considered to be too heterogeneous in terms of the study design and outcome measures for pooling.

Results of the review
Five RCTs and 7 comparative studies were included. Eight studies (3 RCTs) focused on involving users as service providers (where stated, the total number of users was 23 and the total number of clients was 1,679); 2 studies (1 RCT) looked at the effects of involving users as trainers; and 2 studies (1 RCT) considered involving users as interviewers.

Most of the included studies involved few users and had substantial methodological weaknesses. Studies of users as service providers mostly originated in the USA and were confined to a case-management model.

Employing users in, or alongside, case-management services did not have any detrimental effect on clients in terms of symptoms (1 RCT, 1 comparative study), functioning (2 RCTs, 2 comparative studies) or quality of life (2 RCTs, 1 comparative study). Clients of these services had some improved quality of life (2 comparative studies), showing fewer reported life problems and improved social functioning. Some clients were less of a burden to their families (2 RCTs, 1 comparative study). In some studies, clients of employees who were or who had been users went for longer until hospital admission and fewer clients needed to be admitted to hospital (1 RCTs, 2 comparative studies), or the stay in hospital was shorter (1 comparative study), although the time in hospital was not significantly different in all studies (2 RCTs, 2 comparative studies). Services employing people who were or who had been users did not have lower client satisfaction (2 RCTs, 2 comparative studies). In one study, clients of employees who were or who had been users were less satisfied with treatment at follow-up after one year, but not after two years.

The providers of services who had been trained by users had more positive attitudes towards the users. Clients reported being less satisfied with services when interviewed by users.

Authors' conclusions
Users can be involved as employees, trainers or researchers without detrimental effect. Involving users with severe mental disorders in the delivery and evaluation of services is feasible.

CRD commentary
This review addressed an appropriate question using clear inclusion and exclusion criteria relating to the interventions of interest. The literature search was fairly comprehensive, although only English language studies were considered for inclusion and the possibility of publication bias was not investigated. A systematic approach involving two reviewers.
(who worked independently) was used to assess the relevancy of the included studies and to extract the data. However, it was not stated if there were any disagreements and if so how they would have been resolved. The quality of the included studies was assessed, but it was not stated if this was done at the same time, or in the same way, as the data extraction (i.e. by two of the authors independently). Relevant details of the included studies were clearly presented in tabular format, although a summary of the results of individual studies was not presented. The results were combined appropriately in a narrative summary, due to the heterogeneity between studies in terms of the study design and outcome measures. The authors’ conclusions appear to follow from the results presented.

**Implications of the review for practice and research**

Practice: The authors stated that government policy in the UK strongly supports the development of involving users in the delivery and evaluation of mental health services.

Research: The authors stated that little evidence exists on the effectiveness of programmes that involve users in the delivery and evaluation of mental health services, and that more formal evaluations are needed.

**Bibliographic details**


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**Original Paper URL**

http://bmj.bmjournals.com/cgi/content/full/325/7375/1265

**Other publications of related interest**

This additional published commentary may also be of interest. Peter E. Review: involvement of former or current users of mental health services may improve outcomes in patients with severe mental illness. Evid Based Nurs 2003;6:90.

**Indexing Status**

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This is a critical abstract of a systematic review that meets the criteria for inclusion on DARE. Each critical abstract contains a brief summary of the review methods, results and conclusions followed by a detailed critical assessment on the reliability of the review and the conclusions drawn.