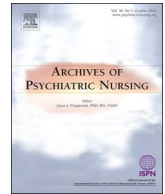




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## Service users' views regarding user involvement in mental health services: A qualitative study

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## ABSTRACT

**Background:** Service user involvement is emphasised in many strategies, plans and declarations globally. However, in practice, service user involvement is not always achieved and remains at a tokenistic level.

**Objectives:** To explore the views of service users on user involvement in mental health service.

**Design:** Explorative descriptive study design.

**Setting:** The study was conducted in one psychiatric hospital and in two mental health organisations in western Finland.

**Methods:** The data was generated through three focus group interviews and analysed with qualitative content analysis.

**Results:** User involvement means that people using mental health services are respected, listened to and can act in co-operation with professionals so that they feel that they can influence their own care and treatment. The participants articulated concrete factors that promote or inhibit user involvement. Service user involvement can be enhanced by strengthening service users' position, by developing the mental health care system and by specific training for professionals.

**Conclusions:** The views of service users in this study concerning the realisation of user involvement and the factors promoting and preventing it were realistic. They are basic elements of patient-centred care and of all human interaction. Our participants described service user involvement in their own care and treatment. They emphasised the need to have more information, and wanted to be more involved in decision-making about their own care and treatment. They called for better care planning and co-ordination as one way to increase service user involvement. These also have implications for mental health services at the system level.

### What is already known about the topic?

- Service user involvement has been identified globally and nationally as an important subject.
- User involvement can occur on many levels.
- In practice, service user involvement is not always achieved and remains at a tokenistic level.
- In mental health services user involvement requires special attention.

### What this paper adds?

- There are still challenges in the realisation of service user involvement in mental health care.

- Service users' interest is more in their own care and treatment than in the mental health care system in general.
- Service users are especially interested in exerting influence in their medication issues.
- Service users see involvement as basic matters like being treated with respect.
- Service users call for better care planning and co-ordination as one way to increase service user involvement.
- Professional judgement and sensitivity are needed for service users to become involved and participate in every stage of their treatment.
- On mental health care system level, creation of care pathways and training of different groups of professionals may be ways to increase service user involvement.

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## Introduction

Service user involvement is emphasised in many strategies, plans and declarations (Storm & Davidson, 2010). In Finland, the national plan for mental health and substance abuse work (Ministry of Social Affairs and Health, 2010, 2014) introduced in 2009 outlined common national objectives for mental health and substance abuse work. The plan emphasised that the client's status must be reinforced; user experts and peers should be included in the planning, implementation and evaluation of mental health and substance abuse work. In many countries, recovery orientation has become the guiding principal in improving mental health services. According to recovery orientation, a person can live a full and meaningful life despite mental ill health and the symptoms caused by it (Shepherd, Boardman, & Slade, 2008). Involving service users is one of the key aspects in recovery focused services (Bower et al., 2015; Slade, Adams, & O'Hagan, 2012).

Service user involvement is often described as a continuum or as a linear model, depending on how much power the service user has (Clark, Davis, Fisher, Glynn, & Jefferies, 2008; Elstad & Eide, 2009). Involvement can occur on many levels. Peck, Gulliver, and Towel (2002) proposed four levels of participation (i) interaction between service users, (ii) interactions between users and health care professionals, (iii) local service management opportunities and (iv) service planning. Tambuyzer, Pieters, and Van Audenhove (2014) stated that involvement occurs on individual (micro-level), health-care service level (meso-level), policy level (macro-level) and on a level including involvement in research and education (meta-level). According to Storm, Hausken, and Mikkelsen (2010), involvement is realised on the one hand when service users participate in their own care and treatment, and on the other hand when they participate in decisions concerning mental health services.

Despite the growing interest in service user involvement, in practice, it is not always achieved (Borg, Karlsson, & Kim, 2009; Laitila, Nikkonen, & Pietilä, 2011), and involvement sometimes remains at a tokenistic level (McCann, Clark, Baird, & Lu, 2008; Omeni, Barnes, MacDonald, Crawford, & Rose, 2014). Service user involvement is a complex concept and difficult to define, and the concepts involvement and participation are often used synonymously (Tambuyzer et al., 2014; Thompson, 2007). Differing definitions may confuse professionals and impede the implementation of user involvement (Storm et al., 2010), and translating involvement into practice is considered difficult (Petersen, Hounsgaard, Borg, & Nielsen, 2012). Millar, Chambers, and Giles (2015) found five key attributes of service user involvement in mental health care: person-centred approach, informed decision-making, advocacy, obtaining service user views and feedback and working in partnership. Based on these attributes they defined service user involvement in the context of mental health care as:

*“An active partnership between service users and mental health professionals in decision making regarding the planning, implementation, and evaluation of mental health policy, services, education, training and research. This partnership employs a person-centred approach, with bi-directional information flow, power sharing and access to advocacy at a personal, service and/or societal level.”*(p. 216.)

In mental health services, user involvement requires special attention because mental health problems may affect users' abilities and motivation to be involved and participate (Tambuyzer et al., 2014). Translating involvement into practice entails that professionals working within those services concentrate on the resources, abilities and possibilities of service users, and on the further development of services (Roberts, 2010). Attitudes of managers and staff are decisive in user involvement (Crawford et al., 2003; Roper & Happell, 2007). Gee, McGarty, and Banfield (2016) identified systemic barriers to user and carer participation. These included professionals' lack of awareness, limited opportunities for participation, slow progress for change, policy issues and mental health culture, including stigma.

Earlier research has shown that service users and providers both value service user involvement but have different views and perspectives on its content (Elstad & Eide, 2009; Omeni et al., 2014; Petersen et al., 2012; Rise et al., 2013). From the service users' point of view, user involvement on an individual level means being able to define one's own needs, to make one's own decisions and to exert influence over daily activities and everyday life, but also to receive support when needed without being subjected to control or coercion (Elstad & Eide, 2009; Petersen et al., 2012). Participation in care planning (Grundty et al., 2016) and shared decision-making (Dahlqvist, Schön, Rosenberg, Sandlund, & Svedberg, 2015) are key components of user involvement.

There seems to be a general consensus on the importance of service user involvement but there is a lack of research reflecting the views and opinions of service users themselves (Gee et al., 2016; Goodwin & Happell, 2006; Omeni et al., 2014; Richter, Halliday, Grømer, & Dybdahl, 2009). To reduce this knowledge gap, we explored the views of service users on user involvement in mental health services in Finland. The study is part of a multi-centre research project intended to develop service users' and carers' opportunities to be more involved in treatment.

The aim of the study was to examine service users' views on user involvement in mental health services. We were interested in service users' views on user involvement at all levels of mental health services. We utilised an explorative descriptive study design (Polit & Beck, 2004). The research questions were:

From the viewpoint of service users

- How is service user involvement realised in mental health care?
- What are the factors that promote service user involvement?
- What are the factors that inhibit service user involvement?
- How should service user involvement be improved in mental health care?

## Method

### Design and data gathering

A qualitative approach was used with focus group interviews as the method of data collection. These focus interviews were used to enable participants to discuss and enrich their views on the matter. Discussions in groups may have led to findings not emerging in one-to-one discussions (Grundty et al., 2016). The methodological orientation was content analysis, which enables the drawing of replicable and valid inferences from data in their context. The aim is to provide a broad description of the phenomenon by creating concepts or categories describing the phenomenon. (Elo & Kyngäs, 2008; Graneheim & Lundman, 2004).

Participants were recruited from one psychiatric hospital and from two mental health organisations in western Finland. The ward is a closed acute ward with 17 beds in a university hospital. The first organisation is a service user organisation founded by experts-by-experience and peer support workers offering peer support and peer-led activities to everyone interested in issues concerning mental health and a substance-free lifestyle. The other organisation is professionally led and offers e.g. rehabilitation services, group and educational activities, voluntary work and recreational activities to people recovering from mental health or substance abuse problems, and people interested in mental health related issues. We wanted to include views from different types of service users in different stages of recovery. The participants were selected by purposive sampling. Inclusion criteria were that they were adults (over 18 years old), had experience of using mental health services and were able to provide informed consent. In each organisation there was a named contact person to inform possible participants about the study. In the hospital, staff members evaluated willing participants' ability to participate and gave them verbal and written information. This was done to confirm participants' ability to give their

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