



FoNS Improvement Insights

Involving Service Users' Stories in Developing Mental Health Services: The Process of Capturing, Enabling and Supporting Service Users' Expertise and Experiences

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Project background

Despite a long tradition of support for service user involvement, there is little evidence that it is an integral part of statutory mental health services. User involvement continues to take a more passive form, where the use of suggestion boxes, patient satisfaction surveys or consultation with service users predominates. Studies have found that professionals have a tendency to control the interpretation of involvement and the ways in which service users are involved. Further studies suggest that service users repeatedly state that the best way for them to have more say in the services which they use, and for their knowledge to become valid in the eyes of service providers, is through better and sustained involvement, as opposed to 'tick-box' exercises. This lengthy project intended to explore and evidence the potential of involvement in local services and was underpinned by the philosophy and values of both recovery and personalisation agendas.

Aims and objectives of the project

This project had two aims; firstly to highlight the perspective of those involved as researchers on both the process and the impact of this type of involvement on them; and secondly to identify significant themes from the service user stories and how these aspects can inform practice within statutory services. To achieve these aims the objectives of the project were to:

- Gather data through the use of service user stories that allows the service user to express their experience of the mental health system without any imposed direction from service providers
- Ensure these stories are not contaminated by service agendas or the need to please by having service users conduct semi-structured interviews with training and support
- Reach those whose views would not normally be heard
- Enable the voices of the 'silent majority' to be heard and to make a difference in influencing service delivery and to be a positive experience for them

Key activities and outcomes of the project

The project was based on participatory action research using three key processes; enabling service users to undertake the role of service user researchers, hearing the service user story and

identifying issues of direct relevance to the service user. Following a launch day advertising the idea, service user applications were received (n=14). Of these, eight individuals completed the researcher training, though only six completed the research project in its entirety. Service user researchers collected service user stories (n=31) using a semi-structured technique for face to face interviews. The stories were audio recorded and transcribed verbatim and analysed using an interpretive phenomenological analysis by the researchers.

Themes were identified relating to both involvement in the process and from the 31 narratives themselves. The stories reveal the lived experience of mental health issues and the services provided. They emphasise the need for the service to focus on the person's whole identity rather than on illness and disorder. The therapeutic effect of narrating or recalling your story has been well documented and has been evident in this project. Several individuals have identified the narrative interview as a turning point in their perception of their illness and recovery to date. This research has highlighted a number of perceived benefits of utilising the narrative for individual and service change, as well as some of the processes and factors which underpin this collaborative approach. It has highlighted an effective and valuing method in which to engage with those whose views are rarely accessed in any other involvement activity.

Implications for practice:

- The use of creative consultation techniques can help people express their thoughts and opinions in a more meaningful way while still providing valuable outcomes that can be used to develop services
- Not only did the involvement of service users as researchers enable the service user participants to give unrestricted stories, it also transformed their identities in the process demonstrating an identity and skills that transcend their condition
- The stories provide a detailed and meaningful history that offer far more information to the service providers than 'assessment' methods alone and can contribute to the strategy of personalised care planning and genuine service user involvement
- Data analysis took much longer than anticipated due to the vast amount of data collected but also was enhanced by the new types of knowledge that the service user researchers brought e.g. their experience of the service, treatment and diagnosis, which added insight and depth to the mapping process

A full project report including references can be accessed from: <http://www.fons.org/library/report-details.aspx?nstd=29098>

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