
Webinar: Service user and carer involvement in mental health care and research

April 19, 2021
15:00 – 17:00 CET

Involvement of service users in mental health has been acknowledged as a ‘good thing’ however, it often remains unclear what it means and how it can be implemented in practice, particularly in South-Eastern Europe (SEE). Such involvement may relate to different aspects of treatment, participation in community advocacy/legislation, and in mental health research projects. In SEE, all three segments are still in their infancy, because their development began in the 2000s. Recently, significant progress has been made about user involvement in research, which was previously a largely neglected area. The European Commission-funded research project IMPULSE (2018-2021) aims to improve the care of individuals with psychotic disorders (<http://impulse.qmul.ac.uk/>). Within IMPULSE, five countries in SEE have successfully set up Lived Experience Advisory Panels (LEAPs). The LEAPs have included individuals with psychotic disorders, who over time developed a very unique expertise in advising mental health researchers on all aspects of the research process. Their contribution has improved the quality of research and helped the interpretation and dissemination of research findings. This event brought together service users, carers, experts and researchers who shared their work and discussed service user involvement in mental health care and research.

A video recording of the webinar is available here: <https://youtu.be/MO4Lm9pYi3o>

Summary of the webinar’s key messages

Main topics discussed:

- Destigmatisation of mental health illnesses
- Engagement with service users in mental health research and services

Learning objectives:

- Overview of different types of service user involvement
- Co-production of mental health services, advocacy, advising researchers
- The role of user-led organizations

First panelist: Prof Norman Sartorius (Association for the improvement of mental health programmes, Switzerland)

Topic: Fighting stigma, 2021

The following text is taken from a synopsis of a similar lecture on stigma, written and presented by Professor Sartorius during 2019 World Congress of Social Psychiatry.

(Sartorius N (2020) Fighting Stigma 2020: Synopsis of the Presentation of the Yves Pelicier Prize Lecture at the World Congress of Social Psychiatry, Bucharest, October 2019. World Social Psychiatry, Vol. 2, Issue 3, September-December 2020.)

Stigma is still attached to mental illness and to all that touches it. The good news is that after the WPA Global Open the Doors program against stigma recent years have seen the development of national and regional programs aiming to reduce stigma in many countries. The experience gained in these programs led to the reformulation of paradigms governing ways of approaching the fight against stigma - a development of great importance because of the likelihood that the stigma of mental illness might become even more pernicious in the future, for a variety of reasons.

In summary, the new paradigms of work against stigma propose that programs against stigma should be directed at well-defined groups of people and that they should be preceded by an exploration of their views and situations in which they will meet people with mental illness. Work against stigma should not be conducted by campaigns but become a routine part of the program of health services, planned, permanent, and funded like any other vital function of the service. In anti-stigma programs, efforts to increase mental health literacy should follow the acquisition of practical skills enabling people to understand and work with people suffering from mental illness. The goal of anti-stigma programs should be a change of behaviour concerning mentally ill people, not only a declaration of changed attitudes. The evaluation of the success of anti-stigma programs should be searched in improvements of laws concerning mental illness, in rates of employment of people with mental illness, in their acceptance in the community, in housing, and opportunities for participation in community life. The ultimate goal of anti-stigma programs should not be that communities tolerate those who are mentally ill but that they include them and treat them as they would any other member of the community.

Stigma remains, for the time being, the main obstacle to the development of mental health services and to the improvement of the fate of people who experience mental illness. It is important to fight against it and use all means possible to prevent it or reduce its consequences.

Second & third panelists: Ms Tihana Majstorovic (NGO Menssana, Bosnia and Herzegovina) & Ms Dženana Nikšić (LEAP member, Bosnia and Herzegovina)

Topic: Service user involvement terminology, and their role in research and services

Forms of service users' involvement:

- Direct help for other users
- Participation in legal legislative processes due to a mental health issues
- Expertise in research projects related to mental health

User led organizations are founded and run by service users. Their goals are for mental health users to take a more active role in creating adequate services for others, be a part of the local community, reduce number of hospitalizations and get more involved in the real life of their communities.

Through service user involvement users have an opportunity to help others, develop new roles, and build credible and valuable relationships with other users. Having users involved in research and services help professionals gain a completely new perspective of their own work and moreover, it enables them to keep their work in touch with reality.

The way to be sustainable as a user-led organization is to be recognizable, especially to the government.

During the presentation, video about MENNSANA's activities was showed. It can be found on the following link: https://youtu.be/F1c_VSRfjR8

Fourth and fifth panellists: Ms Mina Aleksić (NGO Prostor, Serbia) and Ms Bosiljka Brdar (LEAP member, Serbia)

Topic: Presentation of the Guide "Let's work together" which covers the model of successful development of user organizations.

The guide is a useful tool for guiding the development of new user organizations. According to a member of the LEAP group, users consider it understandable and comprehensive and the situation in the mental health system is realistically presented. It can serve users as a source of useful information, but also as an incentive to actively participate in improving the mental health system itself, through their own experiences and observations during their treatment, while clinicians and other professionals interested in developing similar organizations can learn about successful examples in the region. In order for this process to take place successfully, it is important to define the roles of professionals and users in developing a user organization.

The guide is available in English, Serbian, Albanian, Macedonian, Bosnian and Montenegrin here: <http://impulse.qmul.ac.uk/dissemination/lets-work-together-booklet/>

During the presentation, a video on the creation of user organizations in Serbia was presented. It can be found at the following link: <https://youtu.be/3Izhm5q1IKQ>