

## Is user involvement a reality or a dream in LMICs – as well as in the rest of the world?

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Commentary on: Lempp H, Abayneh S, Gurung D, Kola L, Abdulmalik J, Evans-Lacko S, Semrau M, Alem A, Thornicroft G, Hanlon C (2017) Service user and caregiver involvement in mental health system strengthening in low- and middle-income countries: a cross-country qualitative study. *Epidemiology and Psychiatric Sciences* (doi: 10.1017/S2045796017000634).

The paper by Lempp *et al.* (2017) published in this issue of *EPS* together with the companion papers by the same group are invaluable material to make us aware of that part of the world which is still at the margins of our cultural, scientific, ethical and political horizons. This set of papers and the ones which preceded them on this issue inform us about the actual situations in low- and middle-income countries (LMICs), the high potentials for a multifaceted community-based growth of mental health services and the risks that this growth will be slow, not adequately face difficulties and inequalities in access to care, not fight stigma and marginalisation connected to disability deriving from mental health problems. Potentials lay in community characteristics in LMICs, like the presence of volunteer organisations able to work in the community, mutual help experiences, also accumulated in other fields. The picture offered by Lempp *et al.* is characterised by service users' awareness of the meaning of their rights and the extent to which they are deprived of them. Although the practice of service users involvement was unknown, they caught the meaning and the importance very clearly and commented it usefully. Qualitative research is unique in the ability to give us an idea of the potential of individuals and to provide data about something which could not be otherwise addressed, and empirically show what needs are not met and that mental health services can even work against people's dignity and mental health.

Western countries have progressed significantly in service user involvement, although it is likely that

the grey and scientific literature give us an idea which does not completely correspond to the reality. This 'biased idea' concerns either the number of services really implementing such practices and models (many say they do, but often they implement it for a short period and involve only a small number of service users and professionals) and the quality and completeness of their implementation (it is not clear which is the real room and function of peer support, whether and to what extent advance directives and joint crisis plans are respected, how much the user-led evaluation is really taken into consideration, what values are really integrated in user-led services) (Barbato *et al.* 2014; Henderson *et al.* 2015; Segal & Hayes, 2016). Therefore, many mental health services have no sort of user involvement either in an experimental or routine fashion. On a whole user involvement proves to be hard to be implemented at a sufficiently meaningful level, and it may need a much longer and more careful preparation of the background than other practices or interventions which do not actively involve service users.

Although a number of meaningful pitfalls and the frequent 'superficial' fashion in which service users involvement is put in practice in Western countries, and the still sceptical attitudes of many professionals, such model could change and did change to some extent the mental health services in several aspects. In particular, the change has to do with the issue of transparency: the need that service users are aware of what the care pathway consists of – more important in mental health than in physical diseases, where the idea is that there is something 'wrong', rather precisely identified, to be repaired – what will be done for them, on which background and with what expectations. This pertains either to the general transparency that services activities should have in front of service users and the general population as well, and to the relationship between individual service users and professionals. It could also explain why people with mental health problems and their caregivers are often reluctant to refer to the mental health services (not only fear of stigma, or unwillingness to admit that they need mental health care). The right to know how one

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person's mental health problem will be handled, with what aims and in how much time concerns the dimension of human rights, and can be connected to the 'nothing about me without me' statement. 'Compliance' and 'therapeutic alliance' cannot be expected in absence of thorough information, consultation and negotiations and should be the outcome of a change in mentality: professionals have to speak about what they can do and eventually do and service users have to say what they want and do not want and a negotiation can be, when necessary, started. The absence of this attitude made compliance and therapeutic alliance one-way concepts, unpopular among service users. User involvement is useful in having a sharing, negotiating, collaborative professionals' style of work take place either at service and individual level, and it is difficult to imagine that these two levels can develop one without the other.

Service users involvement has the potential to make services less difficult to be understood, used, less far from people and their needs. Even where user involvement is eventually absent, most services have integrated at least part of the user involvement background, and the mentality of professionals and policy-makers has changed. Still, it is worrisome the lack of official acknowledgment of service users role and the fact that the user-led evaluation of services often remains without concrete and serious consequences. Policy-makers state that service user involvement is necessary, but this is not made mandatory (with 'personalisation' being their preferred terms). Academic curricula address this issue insufficiently.

Will the good things of service user involvement as realised in many Western countries be adopted in LMICs starting from the current development phase, and will the mistakes, the cautious and sceptical implementation experiences avoid? Half-way, unconvinced

experiences do not help the growth of mental health services responsive to the real need of people with mental health problems. A more convinced, extended and serious adoption of service user involvement would have the benefit not only to increase users responsibility and empowerment and services responsiveness, but also to better evaluate strengths and weaknesses in order to develop a more useful implementation and have professionals and researchers more sure of its effectiveness and value in mental health services.

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## References

- Barbato A, D'Avanzo B, D'Anza V, Montorfano E, Savio M, Corbascio GC** (2014). Involvement of users and relatives in mental health service evaluation. *Journal of Nervous and Mental Diseases* **202**, 479–486.
- Henderson C, Farrelly S, Borshmann R, Thornicroft G, Birchwood M** (2015). Joint crisis planning in mental health care: the challenge of implementation in randomized trials and in routine care. *World Psychiatry* **14**, 281–283.
- Lempp H, Abayneh S, Gurung D, Kola L, Abdulmalik J, Evans-Lacko S, et al.** (2017). Service user and caregiver involvement in mental health system strengthening in low- and middle-income countries: a cross-country qualitative study. *Epidemiology and Psychiatric Sciences* **8**, 1–11. doi: 10.1017/S2045796017000634. [Epub ahead of print].
- Segal SP, Hayes SL** (2016). Consumer-run services research and implications for mental health care. *Epidemiology and Psychiatric Sciences* **25**, 410–416.