

Rubina Awale¹, Dristy Gurung¹, Ruja Pokhrel¹, Nagendra Bhandari¹, Mark Jordans²

¹Transcultural Psychosocial Organization Nepal (TPO Nepal) ²King's College London, London, UK

Introduction

There is wide recognition about the importance of involving service users and their caregivers in health system policy and planning, service monitoring and research to enhance mental health outcomes. Involvement of service users and caregivers mainly in advocacy, service planning, service monitoring and research has been promoted globally as a strategy to help bolster the health quality of life of service users by improving their mental health. Yet, the evidence base of efforts to do so, and how to do so, is still lacking and this is particularly the case in low and middle income countries (LMICs)

This study aims to explore the potential barriers as well as strategies to involvement and assess the importance of capacity building and their involvement.

Methods

Literature review

- Systematic review to examine the evidence and experience of service user and caregiver involvement in mental health system strengthening.
- Both peer reviewed and grey literature included in the review.

Qualitative Interview

- Qualitative study of service users, caregivers, and representative organizations characterizing the capacity building needs.
- KII with 24 service users and caregivers affiliated to user organizations in Kathmandu and those seeking treatment from health facility in Chitwan

Capacity building

- Two days capacity building training conducted for service users and caregivers on “Mental health awareness and advocacy”
- Capacity building training on Kathmandu and Chitwan districts.

Evaluation Study

- Pre-post evaluation conducted in capacity building training conducted for service users and their caregivers.
- Qualitative interview conducted after period of 9 months of capacity building training. (KIIs- 6 service users and 7 care givers from Kathmandu and Chitwan districts.

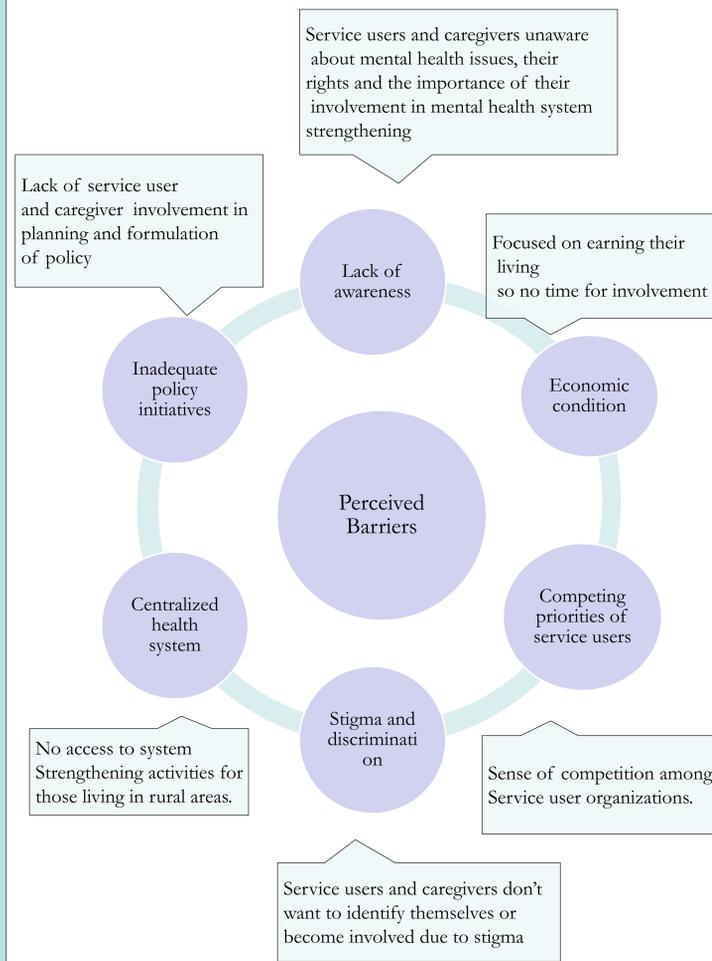
Results

Literature Review

- The review found that that the involvement of service user and caregivers in overall health system policy and planning, service monitoring and research was almost non-existent in context of Nepal.
- The experiences of service users and caregivers with respect to involvement, their achievements and struggles, and their views regarding effective ways to promote service user and caregiver involvement remain undocumented.

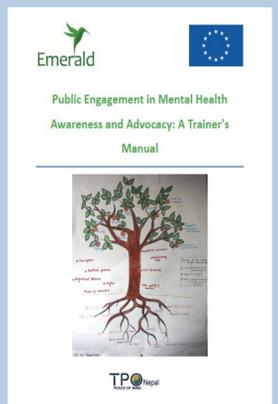
Qualitative Interview

- Participants indicated limited involvement in policy making process and almost non-existent involvement in other areas of health system processes.
- However, many participants showed interest in taking part in such processes if given the opportunity and training



Capacity Building

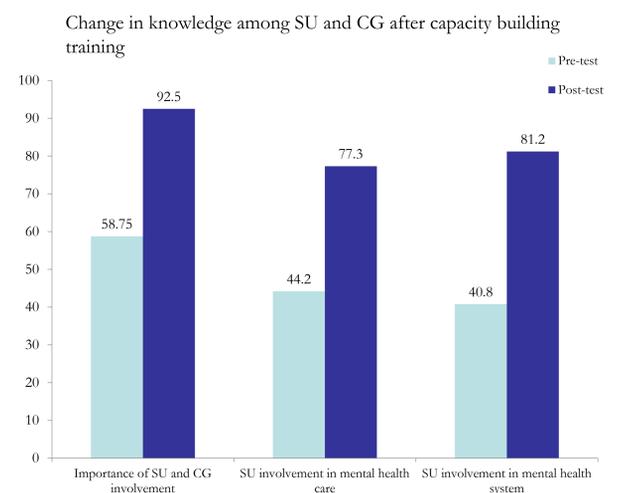
- They have been able to get deeper understanding about mental health issues and about the contributions they can make towards mental health system strengthening.
- Interaction among the service users and caregivers during the capacity building training has helped to establish service user and caregiver network.
- Development of manual on “Public Engagement in mental health Awareness and Advocacy” based on the capacity building training. Manual was developed with support of four service users involved in mental health advocacy



Evaluation Study

- Participants indicated limited involvement in policy making process and almost non-existent involvement in other areas of health system processes.
- However, many participants showed interest in taking part in such processes if given the opportunity and training

“Although there are many programs being organized for policy making, we are not invited. They know we exist, but they don't invite. There are few of us and our voice is not heard. We don't get to participate in the policy drafting.”
(Service user organization representative, Kathmandu, 34, Female)



Conclusion

- Need for improved policy framework and decentralization of care.
- Establishing service user and caregiver organizations to ensure sustainability of service user and care giver involvement.
- Advocacy and awareness
- Anti-stigma campaign
- Capacity building training to enhance the capacity and knowledge of service users and care givers.
- Involvement of service users and caregivers in policy making, in formulation of plans and programs and in research.

Contact details:

Rubina Awale,

Transcultural Psychosocial Organization

Tel no: +977-01-4431717/4437124/4424082

Email: rubinaa.awale@gmail.com