

SERVICE USER AND CAREGIVER INVOLVEMENT IN MENTAL HEALTH SYSTEM STRENGTHENING IN NEPAL

Service user and caregiver involvement has become an increasingly common strategy **to enhance mental health outcomes**, and has been incorporated in the mental health policies of many developed nations. However, this practice is non-existent or fragmented in Low and Middle Income Countries (LMICs). Very little is known about the context of user and caregiver participation in mental health system strengthening processes in Nepal.



METHODOLOGY

This study explores the extent and experiences of service user and caregiver involvement in policy making, service planning, monitoring, and research in Nepal; as well as **perceived barriers to such involvement; and possible strategies to overcome barriers**. Key Informant Interviews were conducted with service users and caregivers who were either affiliated to a mental health organization or receiving mental health care integrated within primary care. Purposive sampling was employed. Data collection was carried out in 2014 in the Chitwan and Kathmandu districts of Nepal.

RESULTS

The involvement of service users affiliated to mental health organizations in policy development was reported to be 'tokenistic'. **Involvement of caregivers was non-existent**. Participants indicated **limited involvement of service users** in policymaking processes and almost non-existent involvement in other areas of national health system processes (i.e. planning and service development, monitoring, and research).

CONCLUSIONS

The study highlighted **the need for user and caregiver networks free from competing interests and priorities**. Improved policy frameworks and decentralization of care may support meaningful service user and caregiver involvement. It shows that **meaningful involvement of service users in Nepal is lacking**, while **involvement of caregivers is simply non-existent**. Among service users, experiences and attitudes towards involvement varied between those who were non-affiliated service users and those affiliated to mental health organizations. **Self-stigma and within-group stigma**, although not mentioned explicitly, was a recurrent theme in the data collected and is one of the major barriers to their involvement. Establishment of user and caregiver networks free from competing interests and priorities (such as those faced by NGOs) was underscored as a strategy to enhance involvement. Improved policy frameworks and improved initiatives (such as those that have been implemented for HIV/AIDS in Nepal) and decentralization of care may support meaningful service user and caregiver involvement.



BARRIERS TO INVOLVEMENT IN NATIONAL HEALTH SYSTEM PROCESSES

STRATEGIES FOR INCREASED INVOLVEMENT

✦ Lack of awareness and information

- Lack of awareness regarding the 'why' and 'how' of involvement among service users, caregivers, and policy makers.
- Lack of confidence to participate due to lack of information.
- Ignorance among policy makers that leads to failure to prioritize mental health.

✦ Raising awareness

- Use of media: posters, radio, TV...
- Incorporation of mental health issues in school education.
- Interpersonal interactions among community members.
- For policy makers: interaction with service users/caregivers, field visits to health centers, awareness workshops...

✦ Stigma and discrimination

- Service users and caregivers feel humiliated and don't want to become involved.
- No space in government positions for service users.
- Psychiatrists unwilling to work with service users on equal grounds.

✦ Reduction of stigma

- Through awareness-raising, education, employment opportunities...
- Getting rid of discriminatory words such as 'service users' and 'service providers'.

✦ Poor economic conditions and competing priorities

- Focus on earning a living, so no time to spare for involvement.
- Expectation of free treatments and medicine, involvement in income generating activities rather than system processes.

✦ Formation of service user and caregiver groups at grassroots level

- Bottom-up approach: service user/caregiver groups should be made in villages
- Supports involvement of service users/-caregivers from rural areas

✦ Centralization of national health system processes

- No access to system strengthening processes for those living in rural areas.
- Health system processes mostly take place in major cities.

✦ Capacity building

- Training should be conducted by the government.
- Training should address basic knowledge of mental illness, its types, and treatments, mental health systems and system strengthening, their needs and roles of service users/caregivers.

✦ Lack of strong leadership and unity among service user community

- Disjuncture among service users representing organizations.
- A sense of competition among service user organizations.
- Conflicting views regarding selection of representatives.
- Lack of consensus on how/to what extent service users should be involved in policy development.

✦ Selection of representatives

- Selection to represent the population from grassroots level.
- Representation of all demographic, economic and geographical groups needed.

✦ Methods of involvement

- Involvement should take place at different levels of policy making.
- Monitoring: formation of monitoring committee with service users, caregivers, service providers, government employees as its members.

REFERENCE

Gurung et al. Int J Ment Health Syst (2017) 11:30
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