Emerald

SERVICE USER AND CAREGIVER INVOLVEMENT IN MENTAL HEALTH SYSTEM STRENGTHENING IN LOW AND MIDDLE INCOME COUNTRIES. SYSTEMATIC REVIEW

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INTRODUCTION

The involvement of mental health service users and their caregivers in **health system policy and planning, service monitoring and research** can contribute to mental health system strengthening; however, to date, there have been very few efforts to do so in LMICs.

A systematic review was undertaken in order to provide an evidence base to inform the **'Emerging mental health systems in LMICs' (Emerald)** programme's capacity-building activities for service users and caregivers in six low- and middle-income countries LMICs (Ethiopia, India, Nepal, Nigeria, South Africa and Uganda).

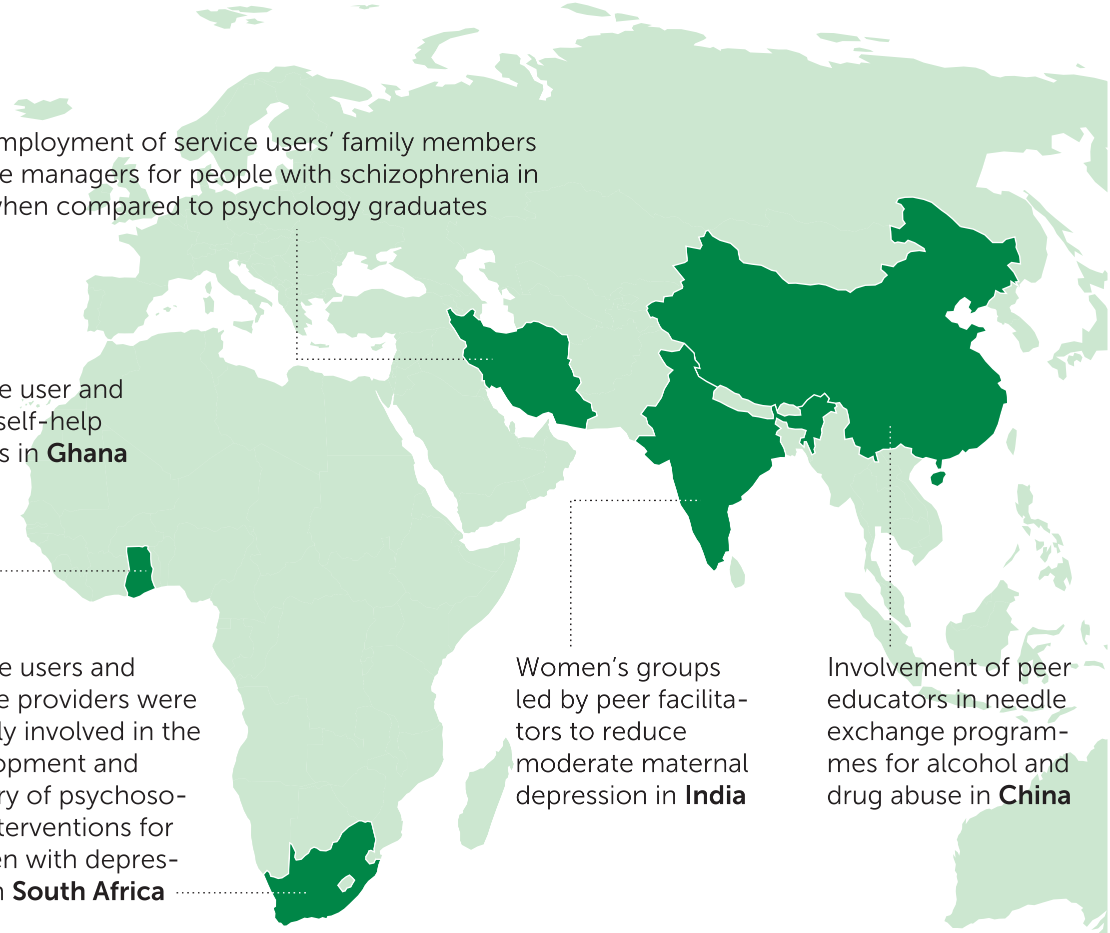
FINDINGS OF PEER-REVIEWED STUDIES

Development of policies or strategies

- Consultation processes with service user involvement are useful and feasible and may lead to an improvement in mental health services and/or outcomes.
- Grassroots public action might address imbalance in power relations when including service users in the decision making processes .
- If service users are not aware or do not have information about their rights, their contribution to policy development is likely to be limited or altogether absent.

Service delivery and support groups

There is evidence for the benefits of service user or caregiver involvement in service delivery and/or support groups. Examples of this are:



The employment of service users' family members as case managers for people with schizophrenia in **Iran** when compared to psychology graduates

Service user and carer self-help groups in **Ghana**

Service users and service providers were actively involved in the development and delivery of psychosocial interventions for women with depression in **South Africa**

Women's groups led by peer facilitators to reduce moderate maternal depression in **India**

Involvement of peer educators in needle exchange programmes for alcohol and drug abuse in **China**

There is still a paucity of **high-quality research,** especially in regards to service user involvement in the development of policies and strategies, the planning and development of services, the training of health workers in mental health care, and within mental health research.

The review showed overall that **service user and caregiver involvement** in mental health system strengthening **is possible and may lead to improvements in mental health services and outcomes.**

Research on service user or caregiver involvement in mental health system strengthening seems to be **on the rise,** as most research has been published **in the last ten years.**

However research findings are **often not translated into practice.**

RECOMMENDATIONS

In a field where a large majority of people do not receive any effective treatment or mental health care, and may at times receive it against their will it is necessary for professionals working within the formal health system to **share responsibility with representative organisations.**

There is a clear need to incorporate **rigorous evaluative elements** of service user and caregiver involvement in mental health system strengthening programmes

More systematic evaluation needs to be incorporated into studies of service user and caregiver involvement, including rigorous study designs with low risk of bias, such as RCTs complemented by participatory approaches or case studies.

Stakeholder involvement in study design is recommended that may offer a solution to the slow translation of the findings into meaningful changes in practice at the service or systems level.

Research needs to take into account **the local context, culture, traditions and values** in the implementation of interventions or capacitybuilding activities.

Encourage stakeholder involvement in study design as a solution to the slow translation of the findings into meaningful changes in practice.

Models of best practice **need to be shared widely** and across countries.

Use research as a platform to provide information to service users and caregivers about their rights, and foster advocacy work. Service users and caregivers should always give their informed consent to participate.

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