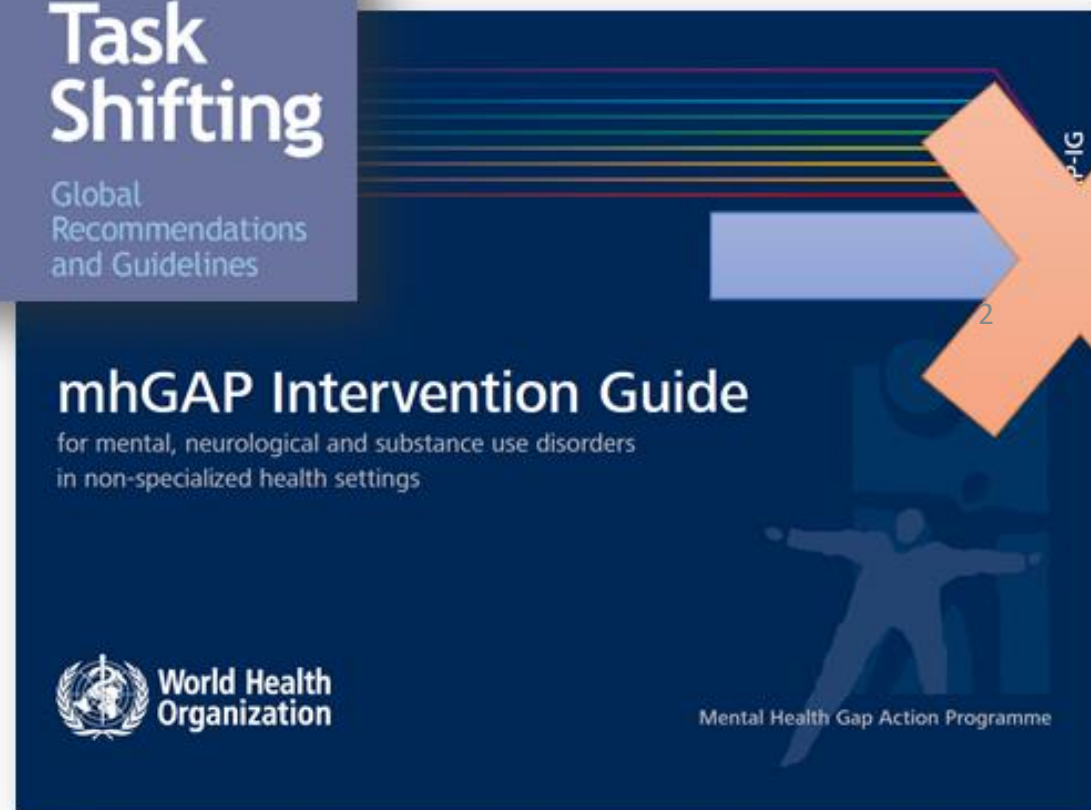
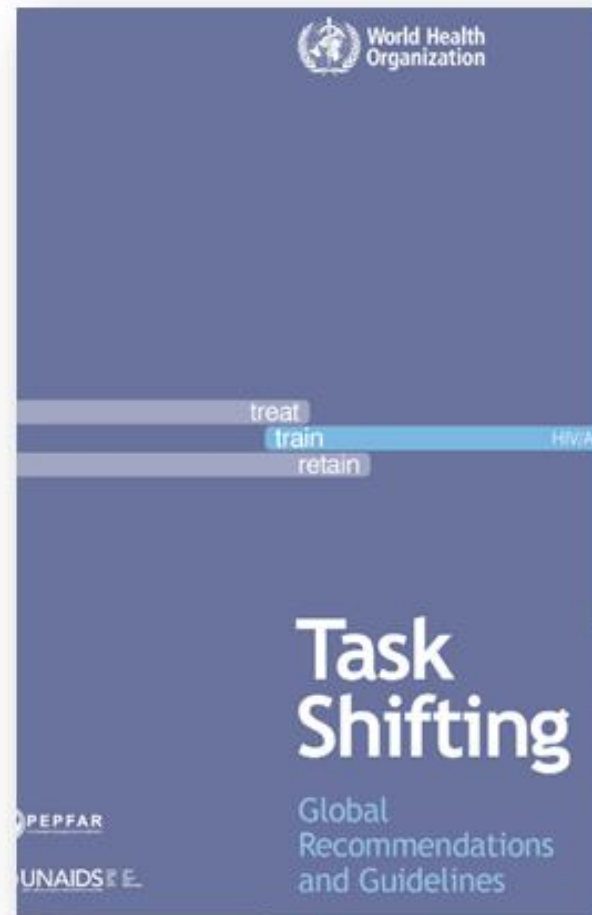

ETHICAL CHALLENGES IN INVOLVEMENT OF PEOPLE WITH LIVED EXPERIENCES (PWLE) IN ANTI- STIGMA PROGRAM IN NEPAL

Lessons from Reducing Stigma
among Healthcare Provider
(RESHAPE) project



Presentation for Global Forum on Bioethics in Research
Dristy Gurung, TPO Nepal

STIGMA AMONG HEALTHCARE PROVIDERS



Stigma among health workers around the world



Photovoice Training

Training in photography and visual narrative story telling.

Participatory research methodology to share agency with community members



EXPERIENCED ETHICAL CHALLENGES WHEN WORKING WITH PEOPLE WITH LIVED EXPERIENCES (PWLE)

Risk of harm associated with participation

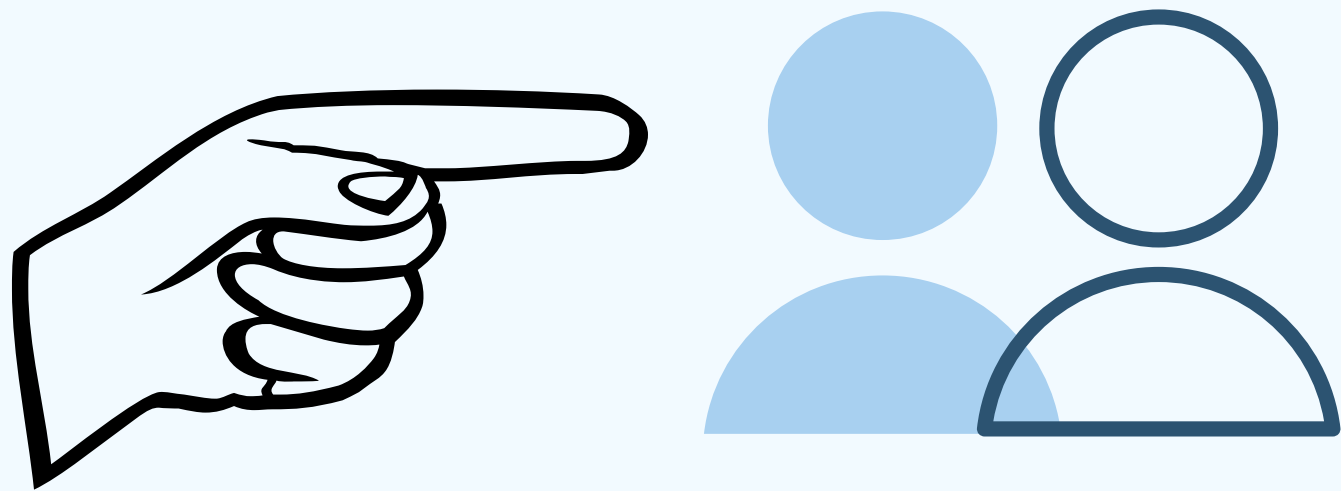
- Risk of increased stigma
- Increased distress

Inequity and inclusiveness challenges

- ⁴ • Challenges in involvement of PWLE with low literacy and from low socio-economic conditions (females, low castes)

RISK OF INCREASED STIGMA

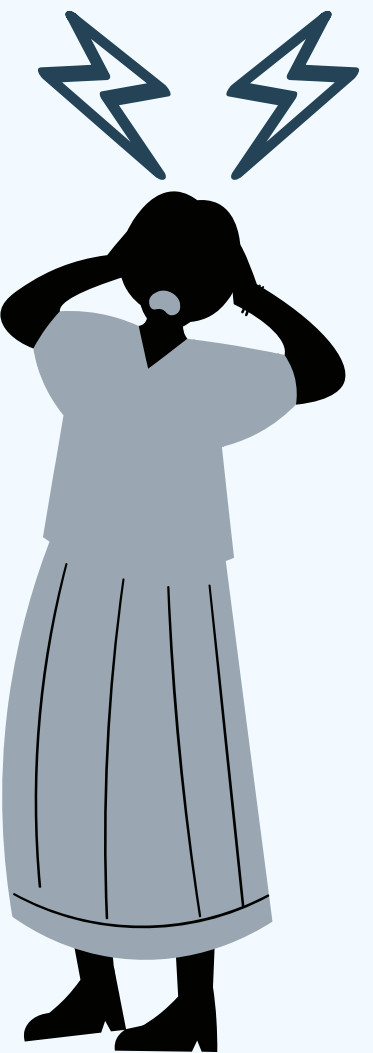
I kept it secret. **I haven't yet revealed what we did in the training and why we went. It is only within our family members** [that people know about the mental health training]. When people used to ask, I used to tell them that there is a training and doctors will come and discuss things. But we did not reveal the truth. **(Male PWLE with depression who dropped out after three PhotoVoice sessions)**



Sometimes I wish that they didn't ask questions to me (laughs). And sometimes I really feel like asking question but I can't. I feel like asking but I feel uncomfortable. **(Female, PWLE with Psychosis)**

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RISK OF INCREASED DISTRESS



Challenge in including PWLE with low-literacy, low functioning, and from marginalized/vulnerable groups such as females

She said that she would go to take part in the training. **I denied her request to join the training because she was a young girl** [22 years old], and I demanded that she not go. I was very worried. **She said that the training was in a hotel. I was afraid where she would go.** I was not sure if it was a “dancing bar” [location of commercial sex work] or washing dishes or talking with boys.
(Father of a female PWLE)

INEQUITY AND INCLUSIVE- NESS



STRATEGIES FOR OVERCOMING CHALLENGES



- Orientation and ongoing information sharing
- Involvement of counselors/mental health professionals during training
- Photovoice as an approach for participation of low-literacy population
- Involvement of family Members or Caregivers

KEY POINTS TO CONSIDER



- Engagement with PWLE **can help reduce stigma** related to mental illnesses
- Ethical challenges such as **risk of harm and inequity in participation** must be considered during engagement
- **Adequate support** (from counselors, caregivers), continuous information sharing, and use of **alternative methods** may help reduce ethical challenges

THANK YOU!

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