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Developing Service User & Caregiver Involvement in Mental Health System Strengthening

*A Training Manual for Mental Health Service Users/Caregivers and
Health Workers in Rural Ethiopia*

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List of abbreviations

CAT:	Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
ICCPR:	International Covenant on Civil and Political Rights
ICESCR:	International Covenant on Economic, Social and Cultural Rights
UNCRPD:	The United Nation Convention on the Rights of Person with Disabilities
LMICs:	Low and Middle Income Countries
UDHR:	Universal Declaration of Human Rights
WHO:	World Health Organization

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Introduction

Background

Mental health system strengthening is an area of concern all over the world. To strengthen the mental health system (policy making, planning, service development and delivery, monitoring and evaluation), the knowledge, skill and confidence of key stakeholders is vital. That includes people with mental health problems.

People with mental health problems have a great deal to contribute to strengthening the mental health system. They have the lived experience of mental illness and can help to make sure that mental health care is developed in the best way to meet their needs. They can identify problems with services and help to find solutions. By working together with people with mental health problems, we can make sure that services are respectful and of good quality.

Capacity building, including empowerment, education, training and mobilisation of people with mental health problems, caregivers, service providers, health service managers and others in the health system is a critical first step to working together to achieve change.

Why this training is needed?

The Federal Ministry of Health of Ethiopia has launched a National Mental Health Strategy to expand access to mental health care. All health workers are now expected to be involved in mental health care, according to their level and ability. Working with people who have mental health problems will help to improve the quality and appropriateness of mental health care in primary care.

In a study from Ethiopia, health workers supported the idea of working with people with mental health problems to improve services, but identified the following key barriers to achieving this goal:

- Not familiar with working with people with mental health problems
- Not knowing how to do it
- Needing more information about roles and responsibilities
- Stigmatising attitudes towards people with mental health problems
- Worry about the traditional health worker-patient relationship

To help to overcome these barriers, we have developed a training programme for people with mental health problems and their caregivers (part I of the manual), as well as for health workers and health service managers (part II of the manual)

Aims

The aim of this training course is to enhance the capacity of primary health care service providers and health service managers to work alongside people with mental health problems/caregivers to improve mental health care in Ethiopia.

Specific objectives are to:

- Equip participants with basic knowledge about mental illness and the context of mental illness in the global, national, and local setting
- Familiarize participants with the concept of involvement of patients with mental health problems in improving mental health care.
- Appreciate barriers to the involvement of patients/caregivers as partners and how to overcome these barriers.
- Give participants the knowledge, skills and attitudes to facilitate development of patient involvement in their local setting.
- Understand the concept of stigma and discrimination, the harmful effects of stigma and strategies to reduce stigma related to mental illness.
- Increase understanding of human rights and human rights-based approaches to working with patients with mental health problems
- Enable health workers to become advocates for people with mental health problems/caregivers.

About this training manual

Development process

This manual has been developed as part of the Emerald project¹ to strengthen mental health systems in Ethiopia. The manual was informed by training needs identified in a baseline study from Ethiopia, the evidence base and experience obtained from other low- and middle-income countries, particularly Nepal and India.

A revised version of both parts of the manual will be prepared after receiving feedback and recommendations from mental health professionals, primary care and mental health care professionals and service user and caregivers who are familiar with the local context.

¹Emerging mental health systems in low- and middle-income countries (Emerald): www.emerald-project.eu

Participants and Parts of the Training Manual

This manual is designed for primary health care service providers, health service managers, service users and caregivers. The manual is proposed to comprise two main parts (i) capacity building training for service providers and health service managers (Part I) designed for one day and, (ii) capacity building training for service user and caregivers (Part II) designed for two days. Both parts are arranged in sections and sessions.

Contents of the manual

To help the participants facilitate the development of service users and caregiver involvement in health system strengthening in their local settings, the content included in the manual is designed to address the barriers to involvement related to gaps in knowledge and skill at various levels: individual service user/caregiver, within the health system and community. Accordingly, the contents of the manual are interdependent and designed in a way that equip service providers, health service managers, service users, and caregivers with practical knowledge and tools to use in their own context.

The training content and a description are presented in Table 1.

Table 1. Summary of training content and brief description

Contents	Description	Service provider/ health service managers	Service user/ caregivers
Basic introduction to mental health and illness	This section is designed to enable service users and caregivers gain basic understanding on mental illness: meaning, causes, types, symptoms, treatment and their role in mental health prevention and treatment	*	X
Understanding service user and caregiver involvement	This topic is included to provide participants with: <ul style="list-style-type: none"> ✓ an understanding of the concept of service user/caregiver involvement, levels of involvement, benefits of involvement, how to involve, and barriers/challenges to involvement and mechanisms to overcome. ✓ an opportunity for participants to think about tangible steps they should take as well as practice skills on how to overcome barriers to service user and caregiver involvement in their local context. ✓ explore what service user/caregivers and health service providers/health managers may need when working towards service user/caregivers 	X	X

	involvement in mental health system collaboratively. It will support the training participants recognize their own inherent strengths and how to identify what they need and what to take actions for practical involvement of service user/caregiver involvement		
Knowledge, attitudes, and behaviors that hinder involvement: The daily experiences of Stigma by service users and caregivers	<p>This section is intended to</p> <ul style="list-style-type: none"> ✓ Help participants enhance their understandings of knowledge, attitudes, and behaviors that contribute to the existing level of service user/caregiver involvement and mental health system/service. ✓ Develop conceptual and practical skills that help participants increase awareness, improve attitude and behavior about knowledge, attitudes, and discrimination surrounding service user and caregiver involvement. ✓ gives the participants a chance to reflect on how stigma and discrimination may impact on them, health service, the health system, the community and economic development as a whole; and design strategies to combat stigma 	X	X
Human rights approach to involvement	<p>The content area is designed to:</p> <ul style="list-style-type: none"> ✓ Familiarize participants with the concepts of human rights, human rights based approach and links between mental health and human rights ✓ Provide basic knowledge on national and international human rights instruments related to mental health and service user/caregiver involvement ✓ Analyze the basic principles of human rights based approach that are important for health service providers and service user and caregiver involvement ✓ Help identify the major human rights violations on service users/caregivers within health system and other social life ✓ Help participants to apply comprehensively human rights-based principles that can be used in everyday practice. 	X	X
Advocacy for mental health and service user and caregiver involvement	<p>This section is designed with the intention to:</p> <ul style="list-style-type: none"> ✓ Introduce participants with the concept of advocacy, characteristics, and benefits of advocacy ✓ Familiarize participants to analyze issues that need advocacy and lobbying in their setting 		

	<ul style="list-style-type: none"> ✓ Assist participants explore important local stakeholders and identify their role in breaking the barriers to service user and caregiver involvement ✓ Help participants gain basic knowledge, strategies, and skills how to develop and implement advocacy campaigns and lobbying for mental health, including service users' and caregivers' involvement within the mental health system, community and other potential resources 		
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* Not included for service providers and health service managers assuming they all already have been trained through mhGap program, and PRIME project. In addition time and funding constraint will allow prioritization

Training/learning methods

The training and learning methods in the manual are based throughout all the training sessions on participatory and active learning principles. Participatory and active learning approaches are particularly appropriate to work with adults who always bring a wealth of personal experience to the learning event. It enables the participants to draw on their own experiences and learn in an active way. Accordingly, both parts of the manual are prepared containing conceptual and practical activities drawn on the nature of the participants, aimed at making the learning /training lively and fun, generating the participants' tacit knowledge. The aim is to get participants actively involved in thinking about the issue of service users/caregiver and mental health system strengthening in their own local context rather than passively listening to a lecture. The participants learn through sharing ideas, discussion and analyzing issues, relating new concepts to their own experiences, trying to find solutions to problems, and planning what they can do to develop service user and caregiver involvement in their own local context. This approach fosters participants' sense of initiative and responsibility and reinforces their ability to think for themselves.

Continued engagement in activities will be central to the training/learning process. Many of the activities of the sessions are designed to help participants come to their own understandings and what they have to do for developing service user and caregiver involvement in their own local context. Hence, training facilitators and its participants are expected to commit themselves to engage in a process of mutual respect, teaching and learning in order to utilize the scientific and experiential local knowledge to generate solution to barriers to service user and caregiver involvement in mental health system strengthening in their local context. The emphasis will be on practical knowledge development and strategies for action.

The activities and methods proposed in both parts of the manual are meant to expand participants existing experience and knowledge through their active participation in the training/learning through brainstorming, practical small group exercise, discussion, reflections, case scenarios, interactive lectures and presentations. In addition the participants will serve as resources for one

another drawing on their knowledge of their respective local experiences to inform the discussion. Through the discussion, group work and sharing of their experiences the participants are expected to learn important skills that help them to facilitate service user and caregiver involvement in mental health system strengthening.

Users of the manual

The manual is mainly for the use by the facilitator(s) to guide the capacity building training for service providers/health service managers, and service users/caregivers. The document provides detailed, step by step instructions on how the facilitators plan and run the training sessions. As the training/learning is expected to be interactive and participant centered, the facilitator need to be creative, responsive to the participants needs, value and respect the experiences of the participants in the training process. It is not prescriptive, “not all—size –fit” and complete by itself. Experienced facilitators can use the manual flexibly, according to the existing situation, context, amount of time available, and the need of participants adding their experience and artistic quality to make the training more successful to achieve the intended objectives. Therefore, the option to adapt or improve training sessions is open to the facilitator making use of the manual.

Structure of the manual

The training manual included step-by step guides in both parts to implement the training including the number of days of the training, sections, sessions per day, objectives of the session, activities, instructions to the facilitator, methods of training/learning and estimated time for the sessions. Each of this is briefly described below to help facilitator prepare in advance for the training.

Sections of the manual

Sections are the major content in the manual that are developed in a way that one is building on the other so as to provide comprehensive knowledge, skills and tools for the participants to help them facilitate in developing service user and caregiver involvement in mental health system strengthening. The manual comprised of five sections in Part I and four sections in Part II.

Sessions of the training

There are seven sessions in Part I and six sessions in Part II. The aim is to have 7 sessions lasting between 40 and 90 minutes per day for Part I and five sessions per day between 40 and 90 minutes per session for Part II of the manual, including coffee and lunch breaks. The training lasts approximately eight hours altogether. The first session and last sessions are described in the next sections whereas the rest are described in detail in the body of each part based on the contents in Table 1.

The first session for both parts of the manual is about **Getting started** the training. This session serves to establish the groundwork for conducting productive training session through fruitful group dynamics. Accordingly, in both parts of the manual there are various activities the facilitator and the participants perform including: participant registration, training material distribution, get to know each other, the participants will disclose their individual expectations, and stipulate, agree on ground rules that will contribute for the successful achievement of the training. In addition this part also includes the pre-training assessment. A pretest is included that should be administered at the beginning of the training session to understand the participants baseline level of knowledge, attitudes, and skills regarding service user and caregiver involvement in the mental health system.

In both parts of the manual there is an **Activity column** for each session. This column outlines the core activities that can be used in each session, with instructions that show the roles and responsibilities of the facilitator and the participants. It has clear procedural **Instructions** for each activity to help the facilitator to structure the session. There is also a **Methods** column that gives hints about how to conduct the session in a way that is highly participatory to give participants time to think, reflect, and discuss activities under each session to facilitate retention and action for change.

In addition, the training materials required for each session are specified: flip charts, markers, laptop and projector, pen, notepads and handouts.

Key points of each section and session are presented for the facilitator to discuss with the participants to agree on a common understanding on the session.

Notes to facilitator. For each section there are detailed notes annexed (as Additional files) for both parts of the manual about each activity to help the facilitators to develop a common understanding of the given activities in line with the objective of the section/session. The facilitator will need to familiarize themselves with the notes and prepare summary notes for presentation **before the training.**

The final session in both parts of the manual is the **Evaluation session.** In this session, the facilitator will gather feedback on the training content and process and reflect on participants learning. In addition post-training assessment is included that should be administered at the end of the training session to understand the changes in participants level of knowledge, attitudes, and skills and the changes after regarding service user and caregiver involvement in mental health system.

Practical tips for the trainer

- Avoid simple explanations, use of too technical terms/jargon and abbreviations and acronyms
- Encourage lively discussion by asking open-ended questions for example “can you tell me about...?”
- Invite participants to answer each other’s question by asking “does anyone have an answer to that question?”
- Be supportive and encourage participants with mental health problems to speak and provide them with space in turn
- Maintain eye contact with everyone in the group when speaking. Try not to favor certain participants
- Keep checking with everyone that the information is clear. Move around the room without detracting the group
- Show that you are listening to individual participants when they speak and reinforce key points to the rest of the group. React to what people say by nodding, smiling, or engaging in other actions that show you are listening
- Be aware of your tone of voice. Speak slowly and clearly
- When appropriate paraphrase participants comments to check that you have understood them properly
- Ask open-ended questions that encourage response.
- At the end of each session, after participants fully discussed the issue, provide a brief summary of what participants mentioned and discussions to ensure that everyone understands the main points
- Encourage participants to share experience with the group. Empathize that you hope that the participants will learn equally from each other as from the training itself
- Ensure that participants understand that there is no hierarchy in the training, and everyone is expected to work together on activities regardless of what their role within their health or community setting is
- At appropriate moments encourage the group to engage in brief energizing activities that involve movement
- In case a participant encounter health problem and if the person seems to be unwell let the participant stop the training session and arrange another time, respectfully encourage the person to have a clinical review.

PART I: A DRAFT CAPACITY BUILDING TRAINING MANUAL FOR SERVICE USERS AND CAREGIVERS

Part I of the manual was adapted from manual entitled “*Public Engagement in Mental Health Awareness and Advocacy: A Trainer's Manual*” developed by TPO Nepal for capacity building training of service user and caregivers in Nepal. The contents of the source manual is contextualized and modified informed by the training needs and recommendation of service user and caregivers in Ethiopia identified in our baseline qualitative study and through a review of the literature.

Aims and objectives

The aim of this training is to build the capacity of service users and caregivers to support their involvement in mental health system strengthening in their local setting. More specifically to:

- Raise awareness about mental health and care
- Familiarise with the concept of involvement
- Discuss knowledge, attitude, and behaviors that hinder service user and caregiver involvement in mental health system
- Provide a forum for service user and caregiver to link together in a network to exercise their rights
- Identify advocacy issue in their local setting for next steps of action

Table 2. Proposed timetable for service user and caregiver training

DAY ONE		
1	Getting started	9:00-4:30
1.1	Participant registration, getting to know each other	9:00-9:10
1.2	Participants expectation review and training objectives presentation	9:10-9:25
1.3	Setting training ground rules	9:25-9:35
1.4	Distribute pre-training questions	9:35-10:05
	Tea break	10:05-10:30
2	Raising awareness about mental health and mental illness	10:30:- 12:30
2.1	Defining mental health and mental illness	10:30-11:00
2.2	Describe types of mental illness, causes and symptoms	11:00-11:30
2.3	Discuss the various treatments for mental illness	11:30-12:00
2.4	Introduce the mental health situation in Ethiopia	12:00-12:30
	Lunch break	12:30-13:30
3	Understanding the concept of service user and caregiver involvement	13:30-15:10
3.1	Describe the concept of service user and caregiver involvement in the mental health system	13:30-13:50
3.2	Describe service user and caregiver involvement in mental health system: level, stages, methods, and benefits/outcomes	13:50-14:20
3.3	Discussion on perceived barriers to service user and caregiver involvement	14:20-14:55
3.4	Group activity-design strategies how to overcome barriers to service user and caregiver involvement	14:55-15:10
	Tea break	15:10-15:40
4	Understanding knowledge, attitudes and behaviors that influence service user and caregiver involvement in mental health system: stigma	15:40-16:50
4.1	Discuss case scenarios, define stigma and identify various forms/types of stigma	15:40-16:05
4.2	Brainstorm and analyze the various level impacts of mental health related stigma	16:05-16:30
4.3	Design strategies to overcome mental health related stigma in the local setting	16:30-17:00
DAY TWO		
5	Human rights-based approach to service user/caregiver greater involvement in mental health system strengthening	9:00-10:30
5.1	Describe major human rights issues related to mental health service users and caregivers	9:00-9:55
5.2	Discussion: international human rights instruments in relation to mental health	9:55-10:30
	Tea break	10:30-11:00
6.	Understanding meaning, processes and strategies for advocacy in mental health, mental service user/caregiver involvement and a way forward	11:00-12:30
6.1	Familiarize with roles of various stakeholders in advocacy for mental health and service users and caregivers involvement	11:00-11:40
6.2	Group activity : problem identification and crafting action plan for enabling service user and caregiver in their local areas	11:40-12:30
	Lunch break	12:30-13:30
7	Close up	13:30-14:10
7.1	Gather feedback and comments on the training	13:30-13:50
7.2	Distribute post-training questions	13:50-14:20
7.3	Closing remark	14:20-14:25

Section 1. Getting started and raising awareness about mental health and mental illness

Estimated duration: 3hours

Number of sessions. This section consisted of two sessions

Number of activities. This section consisted of two major activities and various sub -activities under each session.

Session 1. Getting started: welcome of participants, introduction, expectations, objectives, ground rules and pre-training questions

Total time: 1 hour

Session objectives

- To welcome all the participants of the training
- To introduces the facilitator(s) and participants
- To review the expectations of the participants
- To familiarize participants with the objectives of training
- Establish ground rules that will generate effective work with participants during the training sessions
- To complete pre-test questions to monitor and evaluate the appropriateness of the training

Materials

- Flip charts, markers, papers, overhead projector and laptop , printed copies of pre-training question papers

For Session 1 activities, instruction how to run the training, including methods and time are summarized in the following Table 3.

Table 3. Section 1, Session 1 activities, instruction for facilitator, method and time

Activity 1. Getting started	Instruction for the facilitator	Methods	Time
Activity 1.1. Getting to know each other	<ul style="list-style-type: none"> • Welcome the participants to the training • Introduce yourself by giving your name , work place • Distribute the schedule of the activities/agendas • Explain to the participants the nature of the training session: highly participatory and interactive. including brainstorming,group discussions, practice session, experience sharing and case analysis • Ask the participants introduce each other including names, where they come from... 	Explanation, Brainstorming	10 min
Activity 1.2. Participants expectations review and training objectives presentation	<ul style="list-style-type: none"> • Ask participants to share their expectations of the training and record response on the flipchart • Briefly review the list of expectations in line with the learning objectives listed • Review the training objectives and the specific training activities; be sure to highlight which objectives and activities address participants' expectations. 		10 min
Activity 1.3. Setting training ground rules	<ul style="list-style-type: none"> • Explain that the participants to agree on ground rule for the training so that all participants know in advance that the training will be conducted successfully • Explain that this ground rules are important because they are going to share a lot of personal things and therefore everybody needs to feel 	Brainstorming Discussion	5Min

	<p>comfortable in the group to learn well</p> <ul style="list-style-type: none"> • Read to participants a pre- draft list that includes the following ground rules and explain that these are commonly important rules <ul style="list-style-type: none"> ✓ Keeping time ✓ Mobile phones off or on silent ✓ Respect for each other`s idea ✓ Silence when someone is talking ✓ Active participation ✓ Do not discuss private things outside of the group • Ask whether everybody agrees that these are important rules. • Ask if there are any other ground rules that should be included and add them on. 		
Activity 1.4. Distribute pre-training questions	<ul style="list-style-type: none"> • Inform the participants that they will be given pre-training questions that will contribute to the evaluation of the course • Assure them that this is <u>not a test</u> that they will pass or fail, it is a tool used to help evaluate the training • Let the data collectors conduct the pre-training assessment using a topic guide clearly labeled “pre-test”. 	Individual exercise /interviewer administered	15 min

Session 2.Raising awareness about mental health and mental illness

Total time: 2hour

Session objectives

- Define mental health and mental illness

- Clarify myths, misunderstandings and facts about mental illness
- Describe types, causes and symptoms of mental illness
- Discuss different types of treatments available
- Familiarize participants with mental health situation in Ethiopia

Materials

- Flip charts, markers, papers, overhead projector and laptop , printed copies of pre-training assessment papers

Under this session the activities, instruction how to run the training, including methods and time is summarized in the following Table 4.

Table 4. Section 1, Session 2 activities, instruction for facilitator, method and time

Activity 2.Raise awareness about mental health and mental illness	Instruction for the facilitator	Methods	Time
Activity 2.1. Define mental health and mental illness	<ul style="list-style-type: none"> • Inform the participants about the objectives of the session • Ask the participants what they understand by mental health • Ask the participants what they understand by mental illness • List their response, classify into myths/ misunderstandings and facts about mental illness • Link the answers from participants and define mental health, mental illness, and clarify the myths and misunderstandings with the help of notes to the facilitator(Annex I) 	Discussion Brainstorming Interactive presentation	30min

<p>Activity 2.2. Describe types of mental illness, causes and symptoms</p>	<ul style="list-style-type: none"> • Brainstorm with the group what they think are the possible causes of mental illness • List these one by one on a flipchart • Discuss the list and link items with other possible causes and symptoms of mental illness presented under the notes to the facilitator (Annex I) 	<p>Discussion, brainstorming, presentation</p>	<p>30min</p>
<p>Activity 2.3. Discuss the various treatment for mental illness</p>	<ul style="list-style-type: none"> • Show the PRIME documentary film to the participants • Ask what they saw/felt and learned from the documentary • Ask the participants about the various treatments for mental illness available and sought in their community. • Explain each treatment relating to models of treatment (biomedical, psychological, psychosocial, traditional/spiritual) and discuss about its pros and cons with the participants 	<p>Discussion, brainstorming, presentation</p>	<p>30min</p>
<p>Activity 2.4. Introduce the mental health situation in Ethiopia</p>	<ul style="list-style-type: none"> • Ask the participants what they know about mental illness in Ethiopia and their local area? • Probe about beliefs of society about the causes of mental illness? Sources of service? Availability of service? Government initiatives to integrate mental health into primary health care? • Summarize the session linking it with the notes to the facilitator 	<p>Discussion</p>	<p>30min</p>

Key points

- Mental health problems are part of our shared humanity
- Anyone, everywhere in the world can experience mental disorder
- Mental illnesses are also found in Ethiopia, just like any other countries in the world
- Having a mental disorder is not a character weakness or a result of being deliberately lazy or difficult
- Mental disorders are not the result of curses, magic or evil spirits
- Most people with mental disorders are not violent
- People with mental disorder often need help to recover
- Medication is almost always necessary for the treatment of severe mental illness, together with support and rehabilitation
- Mental health can be treated; recovery from mental illness is possible, with the right support and care, many people with mental illness can live productive and fulfilling lives, including holding a job and get married
- If provided with care, respect, support and treatment, people with mental disorder can meaningfully participate in the community and in their social life

Section 2. Introduction to service user and caregiver involvement in mental health

systemstrengthening

The overall aim of this section is to help service users and caregivers understand the concept and issues related to service user and caregiver involvement so as to encourage their active involvement in mental health system strengthening at local setting. The specific objectives of this session are for participants to be able to:

- Comprehend the concepts of service user and caregiver involvement in mental health system strengthening
- Familiarize participants with levels and benefits of service user and caregiver involvement (individual, organizational, and strategic levels) in mental health system
- Explore the extent of service user and caregiver involvement in mental health system strengthening in their local context

- Discuss barriers to service user and caregiver involvement at individual, organizational and strategic levels in mental health system strengthening with particular focus in their local situation
- Design mechanisms to overcome barriers to service user and caregiver involvement in their local health system

Duration: 1hour 40 minutes

Materials required: printed copies of group exercises, Flip charts, markers, papers, overhead projector and laptop

The activities, instruction to the facilitator, methods and proposed time for each is presented in Table 5

Table 5. Section 2 activities, instruction for facilitator, method and time

Activities	Instruction to the facilitator	Methods	Time
Activity 3. Explain the concept of service user and caregiver involvement in the mental health system	<ul style="list-style-type: none"> ✓ Outline to participants service user and caregiver involvement. ✓ Introduce the participants about the objective of the session 	Explanation Brainstorming	5min
Activity 3.1. Describe the concept of service user and caregiver involvement in mental health system	<ul style="list-style-type: none"> • Ask the participants the following questions to facilitate the discussion: <ul style="list-style-type: none"> ✓ what do they understand by service user/ caregiver ✓ discuss what they want to be called ✓ how can service user/caregiver help to improve mental healthcare for everyone? • facilitate the discussion: try to maximize involvement of participants in the discussion (brainstorm for their contribution in advocacy, awareness 	Brainstorming Discussion Interactive lecture	15min

	<p>raising, self-care, help to develop and improve the service, involvement in management committee and boards etc)</p> <ul style="list-style-type: none"> • Summarize the activity and refer to the notes of the facilitator 		
<p>Activity 3.2. Describe service user and caregiver involvement in mental health system: level, stages, methods, and benefits/outcomes</p>	<ul style="list-style-type: none"> • Ask participants if they have any experiences of being involved in improving mental health care. If they have, then ask those who are willing to share their experiences. • Share the experiences of involvement of service user and caregiver from the qualitative research finding • Brainstorm participants how/in what ways they could be involved. • Ask them their opinion on the importance of service user/caregiver involvement. • Brainstorm on the benefits of service user and caregiver involvement. Ask who benefits and what kind of benefits will emerge from their direct involvement. • Briefly explain various levels of service user/caregiver involvement, methods of involvement and benefits of involvement based on the notes to the facilitator(Annex I) 	<p>Brainstorming Discussion Integrative Lecture</p>	<p>30 min</p>
<p>Activity 3.3. Discuss potential/actual barriers to</p>	<ul style="list-style-type: none"> • Brainstorm with participants about what prevents service user and caregiver 	<p>Brainstorming Discussion</p>	<p>35min</p>

<p>service user and caregiver involvement at individual, organizational and strategic levels in mental health system strengthening with particular focus on their local situation</p>	<p>involvement in mental health system and their social life?</p> <ul style="list-style-type: none"> • Encourage the participants to provide as many views/examples/perceptions as possible to discuss barriers relating to individual service user/caregivers, service providers, health organization, local community and health system 	<p>Integrative Lecture</p>	
<p>Activity 3.4. Discuss how best to overcome barriers to service user and caregiver involvement in their local health system</p>	<ul style="list-style-type: none"> • Ask participants to suggest mechanisms to overcome barriers to service user and caregiver involvement. • Encourage the participants to provide as many activities, strategies, roles and responsibilities of various level individuals and organizations to overcome the barriers(including the roles of service user, caregivers, health service providers, a health service managers and others in the health system) • Summarize the session based on the information provided under the notes to the facilitator 	<p>Brainstorming Discussion Integrative Lecture</p>	<p>15min</p>

Key points

- There are various terms used for calling people with mental illness and the terms preferred by people with mental illness to be called that are helpful
- Service user and caregiver involvement in mental health system can be possible, is important for mental health system strengthening and enhance the recovery process of people with mental illness
- Service users and caregiver are experts by experience; their involvement enables service providers to tap into the wealth of knowledge and experience to improve the service
- Service user and caregivers have crucial roles in all areas of the mental health system, including program design, quality assurance and program evaluation and can shape service provision for both service users and caregivers
- Creating an appropriate environment for involvement through respect, recognition and valuing the expertise and experience of service user/caregivers, gained through experience is critical, and therefore ongoing training and support are crucial success factors
- Involvement requires time, including the development of collaborative and trusting relationships with service user, caregivers, service providers and others within the health system
- Service user and caregiver groups organization and representation in boards and committees is essential for strengthening service user and caregiver involvement in health service quality improvement

Section 3. Understanding knowledge, attitudes and behaviors that influence service user and caregiver involvement in mental health system: stigma

Objectives

The overall objective of this section is to provide a general understanding of stigma towards service user and caregivers at various levels of the health system and community so that service

users and caregivers are involved to overcome stigma and discrimination in their local settings. The specific objectives of this session are for participants to be able to:

- Discuss the meaning and forms/types of stigma related to mental illness with particular emphasis to service user/caregiver involvement in mental health system and their social life
- Analyze examples of stigma within the health system, the society public and individual service user/caregiver level
- Familiarize participants with the multidimensional effect/impacts of stigma related to mental illness at various levels, with particular focus on service user and caregiver involvement
- Design an action plan to combat stigma towards service user and caregiver involvement in mental health system strengthening and in their social life

Estimated duration: 1hour20 minutes

Materials required: Flip charts, markers, papers, and overhead projector and laptop

This section is comprised three specific activities that will give participants a better understanding of the concept of stigma, its forms, levels, mechanisms to combat it including overview of the relevant national and international laws and human rights instruments to protect service user/ caregivers.

Table 6. Section 3 activities, instruction for facilitator, method and time

Activities	Instruction to the facilitator	Methods	Time
Activity 4. Explain knowledge, attitude and behaviors related to mental illness and service user and caregiver involvement: stigma	✓ Explain to the participants the underlining issues related to lack of knowledge, attitude, and behaviors that hinder service user and caregiver involvement.	Explanation Brainstorming Discussion	5min
	✓ Introduce objectives of the session		
Activity 4.1. Discuss stigma	• Brainstorm with the participants the	Brainstorming	20min

<p>related to mental illness: definition, types/forms</p>	<p>concept of stigma</p> <ul style="list-style-type: none"> • Read the case scenarios 1-3 one by one and discuss what they learned from situation/ description. • List the stigmatizing attitudes and behaviors on flipchart. • Summarize the activity 	<p>Discussion Interactive Lecture</p>	
<p>Activity 4.2. Analyze extent and effect of mental health related stigma on health system in general and service user/caregiver involvement particular with specific focus on their local context.</p>	<ul style="list-style-type: none"> • Divide the participants in pairs or groups and ask them to discuss their experiences of stigma - either direct, or indirect, those experienced by family members or others in the community. • Ask them to discuss where such stigma took place and what its impact was. • If appropriate, the facilitator can share his/her own experiences of stigma to the group or show a case study. • Ask participants to provide examples of how stigma takes place in various places such as: family, school, workplace, health centres, community, and government • Ask participants what they thought about the impact of stigma and discrimination on themselves and the (extended) family. List them on the flipchart and discuss. 	<p>Small group discussion and reflection Brainstorming Discussion Experience sharing Interactive Lecture</p>	<p>25min</p>
<p>Activity 4.3. Explore how best to overcome stigma related to service user and</p>	<ul style="list-style-type: none"> • Divide the participants into 3-4 groups. • Ask each group to list out possible sources of stigma (people and 	<p>Small group exercise Reflection</p>	<p>30min</p>

<p>caregiver involvement in their local health system</p>	<p>places)and discuss different ways of reducing stigma- what needs to be done on an</p> <ul style="list-style-type: none"> - Individual level - Health facility level - Community level - National level <ul style="list-style-type: none"> • Ask the groups to present them to other participants • Encourage the group to provide as many activities, strategies, roles and responsibilities of various level individuals and organizations to overcome the barriers(including the roles of service user, caregivers, health service providers, health service managers and others in the health system) • Summarize the session based on the notes to the facilitator(s) 	<p>Brainstorming Discussion Interactive lecture</p>	
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Case scenarios

Case scenario 1

Grum is a 28 years old with mental illness in one rural district in Ethiopia. In an interview conducted with one independent researcher he said “ How do you learn and come to ask me that I have mental illness? I think only my families know about my problem because I have been home hiding myself from others for the last two years. I did not contact any one before... I am mentally ill. I am useless and never able to do what I want to do and expected of me. I will never amount to anything because I have a mental illness. I believe that if I cannot do something , people will not accept me and exclude me from all life domains. ...Yes they are right if they do that because I add nothing. How can a mentally ill person participate in productive society? I am valueless even compared to people with physically disability ...they can participate in productive life but...I cannot for my difficulty is on my main part of the body. You know how my whole life is full of crisis I am economically poor, have no education.”

Case scenario 2

Yihun is 63 years old helping professional with rich experience in the area of mental health as service provider, health service managers at primary health care, regional level and planning at federal level. An independent mental health consultancy organization working in Ethiopia interviewed him to explore the experience, barriers and facilitators to service user involvement in Ethiopian health system with intention to develop service user and caregivers in Ethiopia. Part of the interview dialogue is presented as follows.

Interviewer: In your long experience of work in the area of mental health system have you experience of involving service users in the health system in areas like policy development, planning, mental health strategy development, service delivery ?

Yihun: Do you mean people with mental illness... No ...no...there is no such culture wherever I have been working in all level of health system in the country. After all what people with mental illness contribute? I believe what people with mental illness “contributedoesn't really matter to what we do and I and all my colleagues believe there will be no added value of people with mental illness.”

Interviewer: Do you think that service user can involve in service deliver and quality improvement at the primary health care level?

Yihun: I do not think so. As I told you before there is no such culture in the health system. Even the service is not available in most primary health care centers in most regions of the country... There are many important health problems we have to prioritize in terms of budget and human resource compared to mental illness. I strongly sure people working in the middle level (regions) and lower level (district) as well as health facility level also share my believe. You see, this believe is “part and parcel of the whole value system in our health system”.... The contribution of people with mental illness is not observable... I have strong opinion ... leave alone we the educated and working in the health system the family of people with mental illness and the community share the same believe.

Interviewer: Do you think people with mental illness can organize themselves and contribute in mental health advocacy and involve in self help groups and other productive activities like that of people living with HIV/AIDS?

Yihun: Still I have reservation... people living with HIV/AIDS are very strong, they are empowered, they have funding and support both from the government and non-governmental organizations. People with mental illness are not empowered, have no organization, have no training and they do not have the resources... therefore; I am very doubtful about its viability.

Case scenario 3

Burtukan is 42 years old caregiver to her daughter for the last 12 years. In one study conducted by the independent consultancy organization shared the following experiences of her life as follows

“... I do not wish mental illness to my enemy. ... All your friends turn their back if you have relative with mental illness at home. You face stigma and exclusion in your own community, relatives and friends. When people know you or your family member having mental disorder they point out accusing fingers to you or your relative. You hear people talking about you that you are the cause of the problem as a result of curse or punishment God for your misdeeds that give you headache. People misjudge you as cause of the illness you and your relatives have before accepting you. How annoying and heartbreaking it is... Mental health system is bad. There is no sufficient mental health service in our setting. In the health facilities the health professionals are not treating patients in good manner...; they do not advice you about doing better things They blame us... they do not give us hope... they so seeds of doubt.... We never speak for our rights; we have fear ... if we speak about our rights we will not get the service that we used to get by losing our dignity. I tell you the traditional healers and religious fathers are by far better, they listen to us, even if it is curse or punishment they will help you... they talk about the solution and the problem of the patients...build our hope and tell us do some good things...

Key points

1. Mental illness related stigma exist for various reasons
 - People with mental illness are sometimes stigmatized and discriminated against because they think and behave differently
 - There are various misunderstandings and myths about mental illness and people who live with mental illness
 - Not knowing the facts (knowledge) about mental illness sometimes make people afraid of those who have a mental illness
2. Mental illness related stigma affects a person with mental illness, the family, and health service
 - People with mental illness face rejection (social isolation/exclusion) by friends, relatives, neighbours, employers and sometimes from health professionals
 - A person who is rejected may feel more lonely and unhappy and this will make recovery even more difficult
 - Stigma is harmful to people with mental illness, caregivers, communities and health practices
 - Stigma also affects their family and caregivers of a person with a mental illness
 - Stigma can cause delays in seeking treatment for a family members with mental illness
3. Mental illness related stigma can be reduced through various ways
 - People with mental illness should be seen as active and valuable members of the community
 - The meaningful involvement of people with mental disorders and their caregivers in decisions and programmes that affect them directly is the most successful strategies for reducing stigma
 - Openly talk about mental illness in the community to help people understand that a person with a mental illness is a human being and is therefore entitled to be valued as such
 - Provide accurate information to people with mental illness , caregivers/family and the community groups on what causes mental illness, how common they are, and that

they can be successfully treated

- Involve people with mental illness and caregivers in awareness raising campaign, mental health advocacy and within community and self-help groups

Section 4: Human rights -based approach to service user/caregiver greater involvement in mental health system strengthening

Objectives of the section

The overall objective of the section is increasing service user and caregivers' awareness about human rights-based approach for promoting their involvement in mental health system strengthening and their social life. The specific objective of the section is to:

- Acquire basic knowledge about the concepts of human rights, human rights-based approach and stress the link between human rights and mental health
- Familiarize participants with national and international human rights instruments related to service user and caregiver involvement in health system and other social life.
- Describe the major human rights violations on service user and caregiver

Estimated duration: 1hour 30 minutes

Table 7. Section 4 activities, instruction for facilitator, method and time

Activities	Instruction to the facilitator	Methods	Time
Activity 5. Introduce the concept of human rights-based approach to mental health: meanings, characteristics, benefits and national and international instruments	<ul style="list-style-type: none"> ✓ Explain to the participants in this session you are going to discuss about human rights and human rights-based approach to mental health and service user/caregiver involvement. ✓ Introduce objective of the session 	Brainstorming Discussion Explanation	5 min
Activity 5.1. Describing the major human rights issues related with service user/caregivers	<ul style="list-style-type: none"> • Read for the participants the hypothetical case study report presented under notes to the facilitators on human rights violation of persons with mental health problems. Present the case description without saying violation and then discuss with participants • Ask them what aspects of human rights have been violated in this case example. • Ask the participants to discuss the major human rights violations of service user/caregiver in their local area. • Discuss human rights violations from different perspectives, including at home, in the community, within the health system other areas. • Ask the participants the importance of human rights based approach to protect the rights of service user/caregiver 	Brainstorming Small group exercise Reflection Discussion Experience sharing	50min
Activity 5.2. Discuss national and international	<ul style="list-style-type: none"> • Brainstorm what human rights instruments(laws, policy)they know that help to protect the rights of service user/caregivers 	Brainstorming Discussion Interactive	35min

human rights instruments	<ul style="list-style-type: none"> Briefly describe about Ethiopian human rights instruments embedded in the Federal Constitution 	Lecture	
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Case study

Tamiru is 35 years old living in a rural town. He studied till 10⁺¹ and was employed as office manager in one government organization. He was with his wife and was living harmonious life. 2000 E.C for unknown reason he has developed mental illness. After that he went through a crisis situation. He started to pass his time at home hiding himself from others. Due to his mental illness he has lost his job. When his mental illness increased his wife left him. No one of his families and friends comes to visit him. Finally his mother took him to live with her. When his mental illness further increased he started destroying properties at home and run to street bare. To keep him from damaging properties and from street his mother locked him at separate room during the nights and chained him to a tree during day times. He chained around home for the past 10 years with infrequent release from the chain only whenever he calmed down.

→ Discuss

- Brainstorm what they have conceptualized from the report
- Ask them what human rights violation they have noticed

With his chain she took him to traditional and spiritual healers. At both healing centers they beat him severely with a belt saying that he is possessed with evil spirit. He had wounds all over his back you can see. After long stay with traditional healers she returned him home and continued chaining him to a tree. His hand and legs chained to tree get wounded and when reached about to lose his hands and leg she resealed him out to street. When released out he started destroying properties in his village. In the village people beat him, shouted at him and his mother. Some of

the community of the village decided that he should be sent out of the village, while others said he should be admitted to the mental hospital and not to be brought back to the village because he will always make troubles in the neighborhoods.

→ Discuss

- Brainstorm what they noticed from the report
- Ask them what human rights violations they have noticed
- Ask if they know true similar cases in their locality

His mother cried at the village community expressing her long time suffering with her son. I tried to keep him around home by tying him to a tree for the last 10 years. All people call him crazy and some beat him with stone where he is tied. As you all know there is no mental health service in our area. When asked about mental health treatment in our area the officials say mental illness is not our urgent priority compared to physical illness. It is very difficult to take him to big cities hospital people with mental illness with our socio-economic status. Even in the far hospital I took him last time the service providers are not treating me with good manner; they beat my son; the medication is costly that I cannot afford. They ask for certificate for free medication. Getting certificate that I am “poorest of the poor” from our *Kebele* for free medication is very difficult. I have sold all my property including my land for my son`s treatment. Now I have completely drained all my possession and very tired with all this. I am now in condition where I even begged to people to by me a cup of tea. He is locked inside my house without food and cloth. No one is with me; all my relatives turned their backs. What can I do what God has given me ...

→ Discuss

- Ask the participants what important issues Tamiru`s mother talked about
- Ask what human rights violation issues she talked about
- Ask them if they know similar true cases in their local setting
- Ask them what support they could offer to help Tamiru and his mother if they were in their *Kebele*?

Key points

- People with mental illness and their caregivers/family have human rights like anyone and

should be able to access those rights

- There are national and international laws to protect the rights of people with mental illness and their caregivers in Ethiopia
- Service users and caregivers are entitled to be involved effectively in decisions about their health, well-being, take an active role in their health care and decisions about the provision of health services and to influence and shape the service they receive
- Respecting and protecting the basic civil, political, economic, social and cultural rights of service user is essential for the promotion of mental health and reduction of stigma and discrimination.
- Service user and caregiver can be involved to reduce stigma and discrimination by advocacy for the implementation of laws that ensure people with mental illness are treated fairly and given respect
- Organizing service users and caregivers self-help groups will assist in the promotion of mental health and the protection of human rights for service user and caregivers

Section 5. Advocacy for mental health and mental service user/caregiver involvement, and close up

Objectives of the section:

The overall aim of this section is to help service users and caregivers to appreciate the concept and their role in advocacy. The specific objectives for participants to be able to:

- Discuss about the concept of advocacy in relation to mental health and mental health service user/caregiver involvement
- Analyze mental health and service user as issue for advocacy in their local contexts.
- Discuss the role of service user and caregiver in mental health and service user/caregiver involvement advocacy
- Outline an advocacy campaign plan in relation to mental health or service user and caregiver for their local setting.

Estimated duration: 2 hour

Materials required: flipcharts, markers, papers, overhead projector and laptop

Table 8. Section 5, Session 1 activities, instruction for facilitator, method and time

Activities	Instruction to the facilitator	Methods	Time
<p>Activity 6. Understanding meaning, processes and strategies for advocacy in mental health and mental service user/caregiver involvement</p>	<ul style="list-style-type: none"> ✓ Explain to the participants how best to advocate and lobby for their protection of their rights ✓ Introduce objectives of the session 	<p>Explanation Brainstorming Discussion Interactive Lecture</p>	<p>5min</p>
<p>Activity 6.1. Identify the roles of various stakeholders in advocacy for mental health and service users and caregivers involvement</p>	<ul style="list-style-type: none"> • Ask the participants who have a role to improve mental health care in their local setting • Brainstorm the roles at various levels: individuals and organizations to improve mental health care and service user /caregiver involvement • Probe for the roles they could have to better mental health care • Ask what can they tell other people to help improve mental health in their community 	<p>Brainstorming Discussion Interactive Lecture</p>	<p>35min</p>
<p>6.2. Outline an advocacy plan for mental health / service user and caregiver involvement in their local setting.</p>	<ul style="list-style-type: none"> • Divide the participants into 2-3 groups. • Ask the participants if they are interested to work to improve mental health care in their local setting • Probe it if it would be helpful to meet as a group again? • Tell the groups that they are now service user/caregiver advocates in their community. Ask them how they will practically utilize the knowledge they have gained on in the training mainly related to service user/caregiver involvement in their 	<p>Small group exercise Reflection Discussion</p>	<p>50min</p>

	<p>district.</p> <ul style="list-style-type: none"> • Ask them to come up with a realistic and manageable activity plan and present them in the group in creative ways (give some ideas if needed such as dramas, songs etc.) • Ask the participants to declarepublically the specific activities that they will undertake to use and transfer the knowledge they have gained through the training and ask them to sign the declaration. 		
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Key points

- Provide accurate information to people with mental illness, caregivers and the community groups what causes mental illness, how common they are, and that they can be treated
- Initiate and support local or grassroots level service user/caregiver groups and involve people with mental illness and caregivers in awareness raising, mental health advocacy within community and organizations
- Target influential individuals, groups and organizations such as health and mental health care providers, families/caregivers, friends, politicians, policy planers, funders, community organizations and media in the anti-stigma campaign

Establish committed service user and caregiver and build in their empowerment to advocate for their own health care plans as a pivotal factor to achieve their involvement in mental health system strengthening

Session 2: close up Objective

The overall objective of this session is to evaluate the success of the training session and to put direction for the way forward.

Time: 40 minute

Table 9. Section 5, session 2, activities, instruction to the facilitator, methods and time

Activities 7: close up of the training	Instruction to the facilitator	Methods	Time
Activity 7.1. collect comments and feedback	<ul style="list-style-type: none"> • Focus on the fact that the training is coming to an end and ask participants to share their opinion about the future use of the knowledge they received over the last two days • Ask the participants to give their opinion about the training • Check and compare the expectations articulated during the opening session 	Discussion Brainstorming	10min
Activity 7.2. request a post-training assessment	<ul style="list-style-type: none"> • Explain to the participants that they will take part in a post-training assessment • Invite the data collectors to gather the post-training assessment • Wrap up the training in a formal manner 	Individual test	30min

PART II: A DRAFT CAPACITY BUILDING TRAINING FOR SERVICE PROVIDERS AND HEALTH SERVICE MANAGERS

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Aims and objectives

The aim of this training is to build the capacity of health service providers and service managers so that they are able to facilitate the development of service user and caregiver involvement in mental health system strengthening in their local setting.

- Familiarize participants with the concept of involvement of patients with mental health problems and their caregivers in improving mental health care.
- Appreciate barriers to the involvement of patients and their caregivers as partners and how to overcome these barriers.
- Give participants the knowledge, skills and attitudes to facilitate development of patient and caregiver involvement in their local setting.
- Appreciate the concept of stigma, the harmful effects of stigma and strategies to reduce stigma related to mental illness.
- Increase understanding of human rights and human rights-based approaches to working with patients with mental health problems
- Enable health workers to become advocates for people with mental health problems.

Table 1. Proposed timetable for service providers/ health service managers training

No	Topics	Time
1	Getting started	8:30-9:25
1.1	Participant registration, getting to know each other	8:30-8:45
1.2	Participants expectation review and training objectives presentation	8:45-9:00
1.3	Setting training ground rules	9:00-9:10
1.4	Conducting pre-training questions	9:10-9:25
2	Understanding the concept of service user and caregiver involvement in mental health system	9:25-10:30
2.1	Brainstorming- the concept of service user and caregiver involvement	9:25-9: 35
2.2	Group discussion and reflection- level, methods and benefits of service user and caregiver involvement in mental health system	9:35-9:55
2.3	Group discussion and reflection-barriers to service user and caregiver involvement	9:55-10:15
2.4	Group activity-deigning strategies how to overcome barriers to service user and caregiver involvement	10:15-10:30
	Tea break	10:30-11:00
3	Understanding knowledge, attitudes and behaviors that influence service user and caregiver involvement in mental health system: stigma	11:00-12:30
3.1	Discuss case scenarios, define stigma and identify various forms/types of stigma	11:00-11:20
3.2	Brainstorm and analyze the various level impacts of mental health related stigma	11:20-11:40
3.3	Design strategies to overcome mental health related stigma in the local setting	11:40-12:30
	Lunch break	12:30-13:30
4	Human rights -based approach to service user/caregiver greater involvement in mental health system strengthening	13:30-14:30
4.1	Brainstorm basic concepts - human rights, human rights-based approach and characteristics of human rights	13:30-13:45
4.2	Group discussion and reflection: major human rights issues related to mental health service users and caregivers	13:45-14:10
4.3	Discussion-national and international human rights instruments in relation to mental health	14:10-14:30
5	Understanding meaning, processes and strategies for advocacy in mental health, mental service user/caregiver involvement and a way forward	14:30-15:45
5.1	Brainstorm the concept of advocacy, processes and roles of different stakeholders in relation to mental health and service user/caregiver involvement	14-30-14:50
5.2	Group discussion and reflection: advocacy campaign , steps and characteristics of successful advocacy	14:50-15:15
5.3	Group activity: problem identification and outline an action plan that enables service user and caregiver in their local areas	15: 15-15:45
	Tea break	15:45-16:15
6	Close up	16:15-16:45
6.1	Gathering feedback and comments on the training	16:15-16:30
6.2	Conduct post-training questions	16:30-16:40
6.3	Closing remark	16:40-16:45

Practical tips for the facilitator(s)

- Avoid simple explanations, use of too technical terms/jargon and abbreviations and acronyms
- Encourage lively discussion by asking open-ended questions for example “can you tell me about...?”
- Invite participants to answer each others question by asking “does anyone have an answer to that question?”
- Be supportive and encourage participants with mental health problems to speak and provide them with turn
- Maintain eye contact with everyone in the group when speaking. Try not to favor certain participants
- Keep checking with everyone that the information is clear. Move around the room without detracting the group
- Show that you are listening to individual participants when they speak and reinforce key points to the rest of the group. React to what people say by nodding, smiling, or engaging in other actions that show you are listening
- Be aware of your tone of voice. Speak slowly and clearly
- When appropriate paraphrase participants comments to check that you have understood them properly
- Ask open-ended questions that encourage response.
- At the end of each session, after participants fully discussed the issue give a brief summary of what participants mentioned and discussions to ensure that everyone understands the main points.
- Encourage participants to share experience with the group. Empathize that you hope that the participants will learn equally from each other as from the training itself
- Ensure that participants understand that there is no hierarchy in the training, and everyone is expected to work together on activities regardless of what their role within their health or community setting is
- At appropriate moments encourage the group to engage in brief energizing activities that involve movement
- In case a participant encounter health problem and if the person seems to be unwell let the participant stop the training session and arrange another time, respectfully encourage the person to have a clinical review.

Section 1. Getting started and understanding service user and caregiver involvement in mental health system strengthening

Estimated duration: 1hour 50 minutes

Number of sessions: this section consists of two sessions

Number of activities: there are two major activities and various sub -activities under each session.

Session 1. Getting started: welcome of participants, introduction, expectations, objectives, ground rules and pre-training assessment

Session objectives

- Welcome all the participants of the training
- Introduce the facilitators and participants
- Review the expectations of the participants
- Familiarize participants with the training objectives
- Establish ground rules
- Conduct a pre-test assessment

Materials

- Flip charts, markers, papers, overhead projector and laptop, printed copies of pre-training assessment papers

Under this session the activities, instruction how to run the sessions m, including methods and time as summarized in the following table 2

Table 2. Section 1, Session 1 activities, instruction for facilitator(s), method and time

Activity 1. Getting started	Instruction for the facilitator	Methods	Time
Activity 1.1. Getting to know each other	<ul style="list-style-type: none"> • Welcome the participants to the training • Introduce yourself by giving your name work place • Distribute the schedule of the activities/agendas • Explain the nature of the training session: highly participatory and interactive, including brainstorming, group discussions, practice sessions, experience sharing and case analysis • Ask each participants to pair up with neighbor, ask the partner`s name, position, 	Explanation, Small group Pair interview /plenary session	10 min

	<p>experience of work, training in mental health area, experience of working with service user and caregiver and unique characteristics and then use this information to introduce one another to the participants in the plenary session</p> <ul style="list-style-type: none"> • Have participants introduce the one they interviewed until all individuals have shared the information. 		
<p>Activity 1.2. Participants expectations review and training objectives presentation</p>	<ul style="list-style-type: none"> • Tell the participants that their expectations are important for the training • Ask participants to share their expectations of the training and record response on the flipchart. Attach the flipchart page on the wall for reference. • Give each participants two blank pieces of papers • Ask each person to think about what they hope to gain out of this training • Ask them to write one expectation that they have for the training program on each sheet of papers • As each person finished writing, tape each piece of paper onto the flipchart under the heading “Expectations”. • Briefly review the list of expectations in line to the objective of the training listed • Review the training objectives and the specific training activities; be sure to highlight which objectives and activities address participants’ expectations. • Ask participants to decide together whether all anticipations are within the scope of the training program 	<p>Share Expectations of the training session</p>	<p>10 min</p>
<p>Activity 1.3. Setting training ground rules</p>	<ul style="list-style-type: none"> • Now explain that the participants need to agree on ground rule for the training to ensure that the training is conducted successfully • Explain that this ground rules are important because participants will share a lot of personal aspects of their lives and therefore everybody needs to feel comfortable in the group to learn well • Stick up /display a pre- draft list that includes the following ground rules and explain that these nearly universal rules that 	<p>Brainstorming Discussion</p>	<p>10Min</p>

	<p>experiences tell</p> <ul style="list-style-type: none"> ✓ Keeping time ✓ Mobile phones off or on silent ✓ Respect for each other`s idea ✓ Silence when someone is talking ✓ Active participation <ul style="list-style-type: none"> • Particularly emphasize to keep time as the training is short and the importance to manage time effectively for the achievement of the intended objectives • Tell the participants that time has been planned carefully for each session • Seek agreement from everybody that these are important rules. • Ask if there are any additional ground rules that need to be included on the list and do so at the request 		
Activity 1.4. Conduct pre-training assessment	<ul style="list-style-type: none"> • Tell the participants that pre-training assessment test is administered to them to obtain an idea of the baseline level of knowledge, attitude, and skills • Assure them that this is not a test that they will pass or fail, it is an evaluation tool as part of the training • Distribute a questionnaire clearly labeled “pre-test” to all participants • Encourage them to answer the questions from their own perspective within the given time. 	Individual exercise	15 min

Session 2. Understanding service user and caregiver involvement in mental health system strengthening

The overall aim of this section is to help service provider and health service administrators understand the concept and issues to facilitate the development of service user and caregiver involvement in mental health system strengthening in their local setting. The specific objectives of this session are for participants to be able to:

- Explain the concepts of service user and caregiver involvement in mental health system strengthening
- Describe level and benefits of service user and caregiver involvement (individual, organizational, and strategic levels) in mental health system
- Explore the extent of service user and caregiver involvement in mental health system strengthening in their local context
- Discuss barriers to service user and caregiver involvement at individual, organizational and strategic levels in mental health system strengthening, with a particular focus in their local situation
- Explore mechanisms how best to overcome barriers to service user and caregiver involvement that they would like to see developed in their local health system

Duration: 1hour 05 minutes

Materials required: printed copies of group exercises, Flip charts, markers, papers, overhead projector and laptop

This section is comprised of one session and one core activity, with four sub-activities that will assist participants familiarize with the concept of service user and caregiver involvement, level, how to involve, benefits of involvement at various levels, the barriers/challenges overcome barriers to involvement in health system.

The activities, instruction to the facilitator, methods and proposed time for each is presented in Table 3. To help participants come to a common understanding after discussion, please refer to the notes to the facilitator to summarize each activity at the end of the session as appropriate.

Table 3. Section 1, Session 2 activities, instruction for facilitator, method and time

Activities	Instruction to the facilitator	Methods	Time
Activity 2. Familiarize with the concept of service user and caregiver involvement in mental health system	<ul style="list-style-type: none"> ✓ Explain to the participants learn about issues related to service user and caregiver involvement. ✓ Explain that this session and the activities they will undertake will help them to appreciate the basic concepts, knowledge, attitude, practices, and tools to facilitate service user and caregiver involvement ✓ Explain the questions prepared for the session and distribute to the group for discussion and reflection ✓ Ask the participants to break into small groups of four to five participants each. ✓ Invite them to sit in groups in order of their birthday (day and month). The aim is to have people in pairs with people they do not already know. ✓ Request to identify a group leader and a reporter ✓ The groups will be maintained for the duration of the training, because the training time is short and they will be meet up several times to build on the work that they are carry out. ✓ Ask the groups to discuss the questions and write their notes on flipchart 	<p>Small group exercise Reflection Brainstorming Discussion Interactive Lecture</p>	5min
Activity 2.1. Describe the concept of service user and caregiver involvement in mental health system	<ul style="list-style-type: none"> • Ask the participants the following questions to facilitate the discussion: <ul style="list-style-type: none"> ✓ What do you understand when you hear about the concept service user/caregiver involvement in mental health system? ✓ Who are service users? Who are caregivers? • Facilitate the discussion, try to maximize involvement of participants in discussion of the exercises presented, provide examples and constructive feedback 	<p>Small group exercise Reflection Brainstorming Discussion Interactive Lecture</p>	15min
Activity 2.2. Describe service user and caregiver involvement in mental health system: level, phases, methods, and	<p>Ask questions to facilitate the discussion about the following aspects:</p> <ul style="list-style-type: none"> ✓ Do you think involving service user/ caregiver in health service system is important? Who benefits from their 	<p>Brainstorming Small group exercise Reflection Brainstorming</p>	15min

benefits/outcomes	<p>involvement? What benefit?</p> <p>✓ Thinking about your own practice, how do you involve service user and caregiver in your health facilities?</p>	<p>Discussion Interactive Lecture Experience sharing</p>	
Activity 2.3. Discuss barriers to service user and caregiver involvement at individual, organizational and strategic levels in mental health system strengthening with particular focus in their local situation	<p>Ask questions to facilitate the discussion about the following:</p> <ul style="list-style-type: none"> • In your view, what prevents service user and caregiver involvement in mental health system? • Encourage the group to provide as many views as possible and articulate barriers that relate to individual service user/caregivers, service providers, health organization, local community and health system 	<p>Small group exercise Reflection Discussion</p>	15min
Activity 2.4. List process stages how best to overcome barriers to service user and caregiver involvement in their local health system	<ul style="list-style-type: none"> • Encourage the group to provide as many activities, strategies, roles and responsibilities of various level individuals and organizations to overcome the barriers(including the roles of service user, caregivers, health service providers, a health service managers and others in the health system) • Bring the groups back together and ask each group to present what they discussed to all participants. • Discuss how practically they have to exercise service user/caregiver involvement in their own context. • Summarize the session based on the basic information (see the notes to the facilitator) 	<p>Small group exercise Reflection Brainstorming Discussion Interactive lecture</p>	15min

Section one key points

- Terms used for calling people with mental illness may have implications for communication, service delivery and involvement, therefore pay attention to the terms preferred by people with mental illness to be called with
- Service user and caregiver involvement in mental health system can be possible, is important for mental health system strengthening and enhance the recovery process of people with mental illness
- Service users and caregiver are experts by experience; their involvement enables service providers to tap into the wealth of knowledge and experience to improve the service
- Service providers and others within the health system need to appreciate the special skills and expertise that service user and caregivers can provide both in their own care as well as in the system with which they have lived experience and which they can change
- Creating an appropriate environment for involvement through respecting, recognising and valuing the expertise and experience of service user/caregivers gained through experience is critical success factor
- Service user and caregivers have crucial roles in all areas of mental health system including program design, quality assurance and program evaluation and can shape service provision for both service users and caregivers
- Different methods and techniques will be needed at different stages and multiple approaches to involvement will be necessary for health systems to be effective in their involvement strategies
- Involve service users and caregivers early before crucial decisions has been made
- Changing organization culture to reflect service user/ caregivers worldview; putting clear structures and processes to support involvement; clarity about objectives of involvement, roles and responsibilities of all parties in the involvement, clarity how to work together in an open manner, identifying the right service user/caregiver for involvement is at onset is vital
- Adequate resources, training and information need to be available to service user/caregiver so they can actively involve and contribute to mental health system strengthening
- Developing service users/caregivers self-help organisations; service user and caregivers representation on advisory and governing boards is another important way in to enhance involvement in the mental health field for improving the quality of service

- Provide complete, objective, reliable, relevant, easy to find and understandable information for service users and caregivers
- Service user /caregivers involvement requires not only economic support, but social support, including listening, acceptance of differences, recognition that service users/caregivers may feel anxious and alienated, recognition their value to work together to change attitudes and systems
- Enable continued face-to-face contact and follow-up with service user/caregiver and service user/caregivers networks in an appropriate way when involvement is required.
- ‘Nothing about us without us’ and/or “If you change nothing, nothing will change”.

Section 2. Learn about lack of knowledge, attitudes and behaviors that influence service user and caregiver involvement in mental health system: stigma

Objectives

The overall objective of this section is to provide an appreciation of stigma and its impact on service users and caregivers at various levels of the health system and community, so that service providers and health service managers can plan and manage to promote service user and caregiver involvement in mental health system strengthening in their local settings. The specific objectives of this session are for participants to be able to:

- Discuss the meaning and forms/types of stigma related to mental illness with particular emphasis to service user/caregiver involvement in mental health system and their social life
- Analyze examples of stigma within the health system, the society public and individual service user/caregiver level
- Analyze the multidimensional effect/impacts of stigma related to mental illness at various levels, with particular focus on service user and caregiver involvement
- Design an action plan to overcome stigma towards service user and caregiver involvement in mental health system strengthening and their social life.
- ?Something for providers also to challenge unhelpful attitudes and behaviors of colleagues in the presence of service users/carers?

Estimated duration: 1 hour 30 minutes

Number of sessions: One

Number of activities: one major activity and three specific activities

Materials required: printed copies for group exercises, Flip charts, markers, papers, printed copies of case scenarios, overhead projector and laptop

This section is composed of three specific activities that will give participants a better appreciation of the concept of stigma, its forms, levels, processes to overcome discrimination, including an overview of the relevant national and international laws and human rights instruments to protect service user/ caregivers.

Table 4. Section 2, Session 1 activities, instruction for facilitator, method and time

Activities	Instruction to the facilitator	Methods	Time
Activity 3. Appreciate knowledge, attitude and behaviors related to mental illness experienced by service user and caregiver: stigma	<ul style="list-style-type: none"> ✓ Participants will learn about the lack of knowledge, attitude, and behaviors that hinder service user and caregiver involvement. ✓ Participants will learn the basic conception, attitude, practices, and tools to facilitate service user and caregiver involvement ✓ Explain that questions are prepared by the facilitator for discussion and reflection ✓ Ask the participants to get together into their small groups 	Explanation Brainstorming Discussion	5min
Activity 3.1. Explore impact of stigma related to mental illness: definition, types/forms	<ul style="list-style-type: none"> • Ask the participants to discuss the following questions: • What do you understand by the concept stigma? • Distribute papers of case scenarios/studies • Invite them to read the case scenarios 1-3 and discuss (see next to this table) • Enquire whether they identified any stigmatizing attitudes, and/or behaviors? • Write a list of stigmatizing attitudes and behaviors on the flipchart. • Ask the groups to present their main points of the group work to all participants 	Small group exercise Reflection Brainstorming Discussion Experience sharing Case scenarios Interactive Lecture	15min
Activity 3.2. Analyze extent and effect of mental health related stigma on health system in general and service user/caregiver	Discuss the following question that may facilitate what consequences of stigma emerge at various levels: <ul style="list-style-type: none"> • what is the impact of stigma on service user and caregivers? 	Brainstorming Small group exercise Reflection Brainstorming	20min

involvement, particularly with the view of their local context.	<ul style="list-style-type: none"> what is the impact of stigma on the service or health facility? On health system? on the society and economy? 	Discussion Interactive lecture Experience sharing	
Activity 3.3. list process steps how best to overcome stigma related to service user and caregiver involvement for their local health system	<p>Ask the participants how to reduce stigma in their local context? Encourage the group to provide as many activities, strategies, roles and responsibilities of various level individuals and organizations to overcome the barriers(including the roles of service user, caregivers, health service providers, a health service managers and others in the health system) Summarize the session based on the notes to the facilitator</p>	Small group exercise Reflection Brainstorming Discussion Interactive lecture	50min

Case scenarios

Case scenario 1

Grum is a 28 years old with mental illness in one rural district in Ethiopia. In an interview conducted with one independent researcher he said “ How do you learn and come to ask me that I have mental illness? I think only my families know about my problem because I have been home hiding myself from others for the last two years. I did not contact any one before... I am mentally ill. I am useless and never able to do what I want to do and expected of me. I will never amount to anything because I have a mental illness. I believe that if I cannot do something , people will not accept me and exclude me from all life domains. ...Yes they are right if they do that because I add nothing. How can a mentally ill person participate in productive society? I am valueless even compared to people with physical disability ...they can participate in productive life but...I cannot for my difficulty is on my main part of the body. You know how my whole life is full of crisis I am economically poor, have no education.”

Case scenario 2

Yihun is 63 years old helping professional with rich experience in the area of mental health as service provider, health service managers at primary health care, regional level and planning at federal level. An independent mental health consultancy organization working in Ethiopia interviewed him to explore the experience, barriers and facilitators to service user involvement in Ethiopian health system with intention to develop service user and caregivers in Ethiopia. Part of the interview dialogue is presented as follows.

Interviewer: In your long experience of work in the area of mental health system have you experience of involving service users in the health system in areas like policy development, planning, ,mental health strategy development, service delivery ?

Yihun: Do you mean people with mental illness... No ...no...there is no such culture wherever I have been working in all level of health system in the country. After all what people with mental illness contribute? I believe what people with mental illness “contribute doesn't really matter to what we do and I and all my colleagues believe there will be no added value of people with mental illness.”

Interviewer: Do you think that service user can involve in service deliver and quality improvement at the primary health care level?

Yihun: I do not think so. As I told you before there is no such culture in the health system. Even the service is not available in most primary health care centers in most regions of the country... There are many important health problems we have to prioritize in terms of budget and human resource compared to mental illness. I strongly sure people working in the middle level (regions) and lower level (district) as well as health facility level also share my believe. You see, their believe is “part and parcel of the whole value system in our health system”.... The contribution of people with mental illness is not observable... I have strong opinion ... leave alone we the educated and working in the health system the family of people with mental illness and the community share the same believe.

Interviewer: Do you think people with mental illness can organize themselves and contribute in mental health advocacy and involve in self help groups and other productive activities like that of people living with HIV/AIDS?

Yihun: Still I have reservation... people living with HIV/AIDS are very strong, they are empowered, they have funding and support both from the government and non-governmental organizations. People with mental illness are not empowered, have no organization, have no training and they do not have the resources... therefore; I am very doubtful about its viability.

Case scenario 3

Burtukan is 42 years old caregiver to hear daughter for the last 12 years. In one study conducted by the independent consultancy organization shared the following experiences of her life as follows

“... I do not wish mental illness to my enemy. ... All your fiends turn their back if you have relative with mental illness at home. You face stigma and exclusion in your own community, relatives and friends. When people know you or your family member having mental disorder

they point out accusing fingers to you or your relative. You hear people talking about you that you are the cause of the problem as a result of curse or punishment God for your misdeeds that give you headache. People misjudge you as cause of the illness you and your relatives have before accepting you. How annoying and heartbreaking it is... Mental health system is bad. There is no sufficient mental health service in our setting. In the health facilities the health professionals are not treating patients in good manner...; they do not advice you about doing better things They blame us... they do not give us hope... they so seeds of doubt.... We never speak for our rights; we have fear ... if we speak about our rights we will not get the service that we used to get by losing our dignity. I tell you the traditional healers and religious fathers are by far better, they listen to us, even if it is curse or punishment they will help you... they talk about the solution and the problem of the patients...build our hope and tell us do some good things...

Section two key points

1. Mental illness related stigma exist for various reasons

- People with mental illness are sometimes stigmatized and discriminated against because they think and behave differently than the usual time
- There are various misunderstandings and myths about mental illness and people with mental illness
- Not knowing the fact about mental illness sometimes make people afraid of those who are with mental illness

2. Mental illness related stigma affects a person with mental illness, the family, and health service

- People with mental illness face rejection by friends, relatives, neighbours, employers and sometimes from health professionals
- It results in social isolation and the withdrawal of support from others
- A person who is rejected may feel more lonely and unhappy and this will make recovery even more difficult
- Stigma interferes with help seeking through label avoidance, adherence to treatment and impedes recovery
- Stigma can cause delays in seeking treatment for people with mental illness and their caregivers

3. Mental illness related stigma can be reduced through various ways

- People with mental illness should be seen as active and valuable members of the community
- Direct personal contact with people who experience mental illness is the best approach in reducing stigma
- The meaningful involvement of people with mental disorders and their caregivers in decisions and programmes that affect them may be the most successful strategies for reducing stigma
- Openly talk about mental illness in the community to help people understand that a person with a mental illness is a human being and is entitled to be valued as such
- Create a local or micro level simple and enduring vision that promotes human rights, social inclusion, full citizenship, and a shared responsibility for change using various mechanisms
- Provide accurate information to people with mental illness, caregivers and the community groups on what causes mental illness, how common they are, and that they can be treated
- Support local or grassroots level involve people with mental illness and caregivers in awareness raising, mental health advocacy and within community and self-help groups
- Initiate and support people with mental illness and their caregivers involvement to define issues, design programmes, undertake research and evaluate programme success
- Target influential individuals and groups such as health and mental health care providers, families/caregivers, friends, politicians, policy planners, funders, community organizations and media in the anti-stigma campaign

Section 3: Human rights -based approach to service user/caregiver greater involvement in mental health system strengthening

Objectives of the section

The overall objective of the section is to increase service providers and health service managers' awareness about human rights-based approach for the promotion of human rights of service user/caregivers involvement in mental health system strengthening and their social life. The specific objective of the section is to:

- Acquire basic knowledge about the concepts of human rights, human rights-based approach and link between human rights and mental health
- Familiarize participants with national and international human rights instruments related to service user and caregiver involvement in health system and other social life.
- Empower staff and health service managers with knowledge, skills and organizational leadership and commitment to achieve human rights-based approach
- something about challenging attitudes/behavior of others towards service users and care givers
- Describe the major human rights violations of service user and caregiver
- Discuss how service providers and health system managers integrate human rights into their activities and protect and respect human rights of service user and caregiver

Estimated duration: one hour

Number of sessions: One

Number of activities: One major and three specific

Table 5. Section 3, Session 1 activities, instruction for facilitator, method and time

Activities	Instruction to the facilitator	Methods	Time
Activity 4. Introduce the concept of human rights-based approach to mental health: meanings, characteristics, benefits and national and international instruments	<ul style="list-style-type: none"> ✓ Discuss human rights and human rights-based approach to mental health and service user/caregiver involvement. ✓ Explain that the activities will help them to appreciate the basic concepts of human rights and human rights-based approach, characteristics, benefits for health professionals and for facilitating mental health promotion and service user/caregiver involvement ✓ Explain that the prepared questions for discussion that will be distributed to the group to reflecton 	Brainstorming Discussion Explanation	5 min
Activity 4.1. Explain the concept of human rights, human rights-based approach, and characteristics in relation mental health	<ul style="list-style-type: none"> • Ask the participants the following questions to discuss: <ul style="list-style-type: none"> ✓ what are human rights? ✓ ask them construct definition of human rights? ✓ what are the characteristics of human rights? ✓ Ask about specific examples of human rights. ✓ Ask them what they know about human rights-based approach. ✓ Ask them how mental health and human rights are related 	Small group exercise Reflection Brainstorming Discussion Interactive lecture	15min
Activity 4.2. Outline	<ul style="list-style-type: none"> • Enquire about major human rights violations of 	Brainstorming	20min

<p>the major human rights issues related with service user/caregivers, importance of human rights based approach to service user/caregiver and health professionals/health managers</p>	<p>service user/caregiver in their local area.</p> <ul style="list-style-type: none"> • Encourage the participants to discuss from different perspective: at home, in the community, within the health system other areas. • Ask the participants to engage with the importance of the human rights-based approach to protect the rights of service user/caregiver 	<p>Small group exercise Reflection Brainstorming Discussion Interactive Lecture Experience sharing</p>	
<p>Activity 4.3. Discuss national and international human rights instruments</p>	<ul style="list-style-type: none"> • Ask the participants discuss any national or international instruments they know. • Encourage to outline human rights included in the federal constitution • Ask participant to feedback and present their main discussion points to all participants in plenary session 	<p>Small group exercise Reflection Brainstorming Discussion Interactive lecture</p>	<p>20min</p>

Section three key points

- People with mental illness and their caregivers have human rights like anyone and should be able to access those rights
- Service providers and health service managers need to understand various human rights instruments and practice with the entire system.
- Acknowledge service users and caregivers are entitled rights to involve effectively in decisions about their health, well-being, take an active role in their health care and decisions about provision of health services and to influence and shape the service they receive
- Respect and protect basic civil, political, economic, social and cultural rights as essential strategy for promoting mental health, reducing stigma and strengthening service user/caregiver involvement
- Ensure service user and caregiver rights to equal opportunity and multiple channels to accessible information, accessible service, rights to consultation and public participation in policy making and service delivery in law or policy and practice.
- Service users and caregivers ability to take responsibility and control over their lives is central to their quality of life
- Organizing and involving service users and caregivers helps for promoting mental health and protecting the human rights of service user and caregivers

Section 4: Advocacy for mental health and mental service user/caregiver involvement, and close up

Objectives of the section:

The overall aim of this section is to help service providers and health service managers to understand the concept of advocacy, skill and procedure for mental health promotion and developing service user and caregiver in mental health system strengthening. The specific objectives for participants are:

- Discuss the concept of advocacy: meaning, characteristics, processes, and strategies for advocacy in mental health service user/caregiver involvement
- Introduce the concept of advocacy campaign planning and basic steps in successful advocacy campaign planning.

- Develop knowledge and skills on to analyse situations that require an advocacy campaign for service user and caregiver in their local context, set specific goals, objectives and indicators for the identified issue
- Outline an advocacy campaign plan for the aspects raised in relation to mental health or service user and caregiver in their local setting.

Estimated duration: 1hour 45 minutes

Number of sessions: Two

Number of activities: Two major activities and various sub-activities

Materials required: printed copies for group exercises, flipcharts, markers, papers, overhead projector and laptop

Table 6. Section 4, Session 1 activities, instruction for facilitator, method and time

Activities	Instruction to the facilitator	Methods	Time
Activity 5.Acquite with the meaning, processes and strategies for advocacy in mental health and mental service user/caregiver involvement	<ul style="list-style-type: none"> ✓ Discuss and agree how best to advocate and lobby for mental health promotion and service user/caregiver involvement in mental health system strengthening. ✓ Explain that the activities will help to learn the basic concepts, processes, steps and strategies to facilitate mental health promotion and service user/caregiver involvement ✓ Explain that questions have been prepared for the session and will be distributed to the group for discussion and reflection 	Explanation Brainstorming Discussion Interactive Lecture	5min
Activity 5.1. familiarize with meaning of advocacy, reasons for advocacy in mental health and its roles for various stakeholders in advocacy	<ul style="list-style-type: none"> • Distribute a flipchart and marker to each participant • Ask the participants the following questions to discuss: <ul style="list-style-type: none"> ✓ what do you understand when you think of advocacy? ✓ ask them construct definition of advocacy ✓ ask their opinion about mental health and mental illness need advocacy? Why? ✓ Ask whether service user/caregiver involvement is an issue for advocacy? ✓ Who need to be contributing to mental health and service user/caregiversinvolvement advocacy? How and what role/function? ✓ Encourage the group to provide as many 	Small group exercise Reflection Brainstorming Discussion Interactive lecture	15min

	<p>activities, strategies, roles and responsibilities of various level individuals and organizations in mental health advocacy and service user/caregiver involvement(including the roles of service user, caregivers, health service providers, health service managers and others in the health system)</p> <ul style="list-style-type: none"> • Manage the time • After the discussion ask each group reflect their work back to the whole participants in plenary session • Summarize the activity based on the notes to the facilitator. 		
Activity 5.2. Introduce advocacy campaign planning and initial steps to plan successfully an advocacy campaign	<p>Discuss the following questions:</p> <ul style="list-style-type: none"> ✓ Experiences of past advocacy work? ✓ What is an advocacy campaign? ✓ What are the characteristics of a successful advocacy campaign? ✓ What are the steps to be followed in planning a successful advocacy campaign? • Summarize the session based on the notes to the facilitator 	<p>Small group exercise Reflection Brainstorming Discussion Interactive lecture</p>	15min

<p>Activity 5.3. Analyse issues that lend themselves for an advocacy campaign for service user and caregiver in their local context.</p>	<ul style="list-style-type: none"> • Ask them to discuss the following questions: <ul style="list-style-type: none"> ✓ What do you think are the basic points and concerns for service user and caregiver involvement that need to be addressed for advocacy work? ✓ Why is it important that these concerns are addressed? ✓ Who are the various bodies that you think and know of that exist in your locality or nationally that you one can access and lobby? ✓ What information do you think is needed for advocacy relating to service user and caregiver involvement? Why? • Encourage the group to provide as many activities, strategies , roles and responsibilities at various levels: individual and organizations to overcome the barriers(including the roles of service user, caregivers, health service providers, a health service managers and others in the health system) • Re-convene the participants again and request each group to report main points back (1-3 points only as time very short • Summarize the points using the notes to the facilitator 		15min
<p>5.4. Outline an advocacy campaign to identify specific issue pertinent to mental health or service users and caregivers in their local setting.</p>	<ul style="list-style-type: none"> • Inform the participants to gather the last time in the same groups • Distribute flipcharts to each group • Tell them draft an advocacy action plan based on the problem they have identified • Ask the participants to focus on what participants want to do practically in their local setting to involve service user and caregiver involvement in mental health care • Emphasize what can be realized in their local setting to involve service user/caregiver in mental health system strengthening • Gather the participants again and ask them to share their advocacy action plan 	<p>Small group exercise Reflection Discussion</p>	30min

Section four key points

- Implementation and sustaining service user and caregiver involvement requires systems that value service user and caregiver expertise and experience to incorporate these values into strategic planning, design, human resource policies and budgeting.
- Service providers and health service managers need to appreciate national and international human rights instruments and practice for the entire health system
- Provide service user and caregiver with information regarding their rights, available services and how they can access and influence them
- Establish service user and caregiver networks and empower them to contribute and participate in their own health care plans, to achieve their involvement in mental health system strengthening
- Target programmes at influential individuals, groups and organizations including friends, families, religious leaders, government, non-government organizations and community based organizations
- Service providers, health service managers and others within government non-government and community organizations with senior leaderships involvement in mental health advocacy, and service user and caregiver involvement, combined with support in the form of organizational structures and infrastructures that can provide a safe infrastructure and environment where involvement can flourish.

**Session 2: close up
Objective**

The overall objective of this session is to evaluate the success of the training session and to put direction for the way forward.

Time: 30 minute

Table 7. Section 4, session 2, activities, instruction to the facilitator, methods and time

	Instruction to the facilitator	Methods	Time
Activities 6: close up of the training			
Activity 6.1.	<ul style="list-style-type: none"> • Focus on the fact that the training is 	Discussion	10min

collect comments and feedback	<p>coming to an end and ask participants to share their opinion of the future use of the knowledge they received</p> <ul style="list-style-type: none"> • Ask the participants to give their opinion about the training • Check and compare their initial expectationsexpressed during the opening session 	Brainstorming	
Activity 6.2. Distribute post-training assessment	<ul style="list-style-type: none"> • Explain to the participants that they are invited to take a post-training assessment • Distribute the post-training assessment • Wrap up the training in a formal manner 	Individual test	20min

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