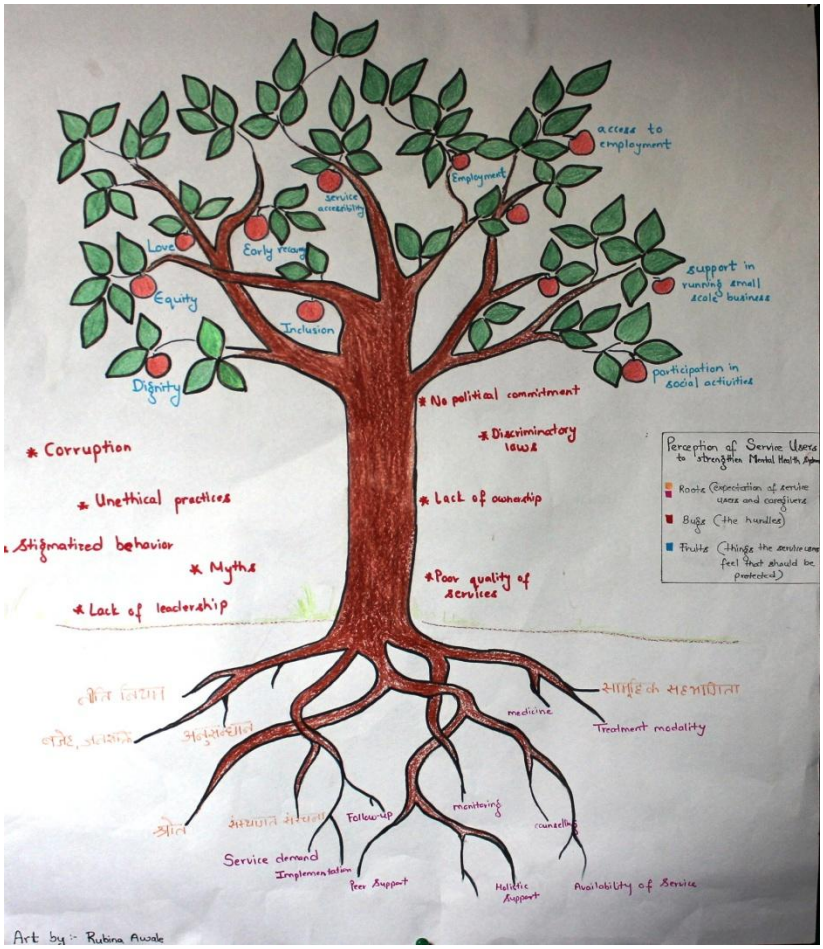
Public Engagement in Mental Health Awareness and Advocacy: A Trainer's Manual



Public Engagement in Mental Health Awareness and Advocacy: A Trainer's Manual

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FORWORD

Service users and caregivers are increasingly recognized as experts by experience. Full participation by service users and carers is vital for effective mental health service planning and delivery. Indeed the evidence for how best to reduce stigma is that this crucially depends upon contact between people who do, and who do not, have experience of mental ill health- so that the service user role is absolutely central.

Yet the concept of service user involvement is poorly developed in many low and middle income countries and there is a lack of information and guidance for service users and caregivers about how to get involved and how to provide and receive the necessary training. I am therefore delighted to introduce '**Public engagement in mental health awareness and advocacy: a trainer's manual'** to you. It is a practical resource for anyone wanting to provide workshops on service users and caregiver's involvement to contribute towards making mental health services and systems better.

This manual has been developed with several rounds of discussion and field-testing with service users and carers. I am confident that it will provide comprehensive guidance to trainers on providing the knowledge and skills necessary for service users and carers to actively engage in policy dialogues, research, and service planning that will make important contributions to strengthening mental health systems in developing countries like Nepal.

I would like to thank TPO Nepal and other mental health stakeholders in Nepal who were involved in the development of this manual, which is a very important part of the work of the EU-funded Emerald consortium as a whole. I hope that you will find this guide interesting and useful in your work.

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LETTER FROM TPO NEPAL

Since its establishment in 2005, Transcultural Psychosocial Organization (TPO) Nepal has been working actively in the field of psychosocial and mental health through several activities ranging from community support to policy making. Within a short period of time it has been able to establish itself as one of the leading Nepalese Psychosocial and mental health organizations.

This **"Public Engagement in Mental Health Awareness and Advocacy: A Trainers Manual"** has been developed with the support of mental health advocates from Nepal Mental Health Foundation and Women's Group for Disability Rights (WGDR) and after testing it in two workshops conducted with people with mental health problems(Service Users) and caregivers in Chitwan and Kathmandu Districts.

The objective of the training manual is to guide the facilitators to run the workshop effectively. We hope that the workshops conducted using this training manual would help participants gain basic understanding on mental health, mental illness, and stigma and discrimination associated to mental illness along with knowledge on different services available for mental health problems, national and international laws related to mental illness. Similarly, we anticipate that the workshops would encourage people with mental health problems and caregivers to become involved in mental health research and other system strengthening processes.

I would like to thank all the organizations and individuals involved in the development of this manual. I would also like to extend my gratitude to Emerald Project for this initiative.

Suraj Koirala

Executive Manager

TPO Nepal

ACKNOWLEDGEMENT

We would like to thank all the persons and institutions that contributed in the development of this manual. Specially, we would like to acknowledge the feedback provided by the participants of people with mental health problems and care givers training conducted in Kathmandu and Chitwan districts in 2015. We believe that shared knowledge, experiences, and perspectives have produced a manual that will have a significant positive impact on the capacity building ofpeople with mental health problems and care givers.

Special thanks are extended to the TPO Nepal Kathmandu based staff and Chitwan based staff for their support in the organization of trainings and in the preparation of this manual.

The preparation of the manual would not have been possible without financial support from the European Union's Seventh Framework Programme (FP7/2007-2013) to the Emerald project under grant agreement n° 305968.

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Women's Group for Disability Rights (WGDR).

SUMMARY

This manual is a part of training initiative under Emerald Project and has been prepared by TPO Nepal in close coordination and collaboration with Nepal Mental Health Foundation (NMHF) and Women's Group for Disability Rights (WGDR). This manual describes the training methods that enable the trainers to explore and mobilize People with mental health problems and care givers' knowledge for mental health awareness and advocacy. The manual provides guidance to select the participants and the methods that can be used to deliver the sessions. The manual contains session plan followed by reading materials for each session. The intention of the training is to build the capacity of people with mental health problems and care givers by making them aware about mental health issues so that they can be co-partners for advocacy in the issues that concerns them and contribute in mental health system strengthening in Nepal.

The training is to be held for two days and the training can be facilitated by experts on mental health along with representatives of service user and care givers so that they can share their personal experiences on various mental health issues. The location and timing of the training can be adapted to suit the target group. The training would sensitize people with mental health problems and care givers on various issues like mental health policies, benefits provided by Nepal government to people with psychosocial disability and involvement of people with mental health problems/care givers in mental health policy formulation, mental health service planning, service delivery, monitoring and evaluation of service quality and mental health research.

ACRONYMS

CEDAW: Convention on the Elimination of All Forms of Discrimination against Women

CIVICT: Centre for Victims of Torture Nepal

CMC: Centre for Mental Health and Counselling

DALY: Disability Adjusted Life Years

HIV: Human Immune Virus

IASC: Inter Agency Standing Committee

ICCPR: International Covenant on Civil and Political Rights

ICESCR: International Covenant on Economic, Social and Cultural Rights

MoHP: Ministry of Health and Population

NCASC: National Center for AIDS and STD Control

NHSP: Nepal Health Sector Programme

NHTC: Nepal Health Training Centre

NGO: Non Governmental Organization

OECD: Organization of Economic Cooperation and Development

TPO: Transcultural Psychosocial Organization

UDHR: Universal Declaration of Human Rights

UN CRC: United Nations Convention on the Rights of the Child

UNCRPD: United Nation's Conventions on the Rights of Persons with Disabilities

VDC: Village Development Committee

WHO: World Health Organization

Table of Contents

Training overview

Selection procedure	Selection of both literate and non-literate people with mental health problems and caregivers through recommendation from service user representatives, health workers, and Female Community Health Volunteers (FCHVs).
Selection criteria	• Critical thinking • Family support • Leadership quality • Interest/motivation • Is able to actively participate
Training methods	Use of group discussions, brainstorming, powerpoint presentations, case study, group activities on three distinct topics, and experience sharing, with focus on visual learning (through pictures, documentaries and video recorded interviews) for non-literate groups.
Declaration/commitment made by the participants	At the end of the training, ask the participants to sign the declaration that includes the activities that they will be doing to use and transfer the knowledge they have gained through the trainings.

Day 1

Lesson Plan: Session 1

Introduction

Total time: 45 Minutes

Objectives:

- To introduce the facilitators and participants
- To collect expectations from participants
- To introduce the training objective to participants

SN	Topic	Activities	Methods	Materials & Resources	Duration	Facilitator
1	Introduction	• Let the participants and facilitators introduce themselves with their name and background information • Give welcome note by facilitator • Ask each participant to share his/her expectations from the training and list them on a flip chart • Share the objective of the training and compare it with the expectations of the participants • Discuss with the participants which expectations would be met through the training and which will not be met • Conduct pre-test evaluation(see Annex I	Introduction, group discussion, evaluation	Newsprint, marker, pre-test evaluation form	45 minutes	

Lesson Plan: Session 2

Introduction to Mental Health

Total time: 1 hour 30 minutes

Objective: The participants will be able to;

- Define mental health and its types
- List down causes and symptoms of mental illness
- Describe different types of treatments available

SN	Topic	Activities	Methods	Materials & Resources	Duration	Facilitator
1	Introduction to mental health	• Inform the participants about the objectives of the session • Ask the participants what they understand by mental health and illness • Link the answers from participants and define mental health, mental illness, and its types with the help of powerpoint presentation	Discussion, brainstorming, presentation	Multimedia	25 Minutes	
2	Causes and symptoms of mental health	• Brainstorm with the group what they think are the possible causes of mental illness • List them down one by one on a board/newsprint paper • Discuss about the list and link them up with other	Discussion, brainstorming, presentation	Multimedia/ newsprint paper, marker	30 Minutes	

		possible causes and symptoms of mental illness through multimedia presentation				
3	Types of mental health treatments	• Show the PRIME documentary (democratizing mental health) to the group • Discuss about different models of treatments mentioned in the documentary and ask them what treatments are available and sought in their community. • Describe about each model (biomedical, psychological, psychosocial, traditional/spiritual) and discuss about its pros and cons with the participants	Experience sharing, discussion, brainstorming	Board/news print paper, marker	30 minutes	
4	Summary and conclusion	• Summarize the main points of the session and conclude the session			5 Minutes	

Reading Material: Session 2

Introduction to Mental Health

2.1. Mental Health

World Health Organization defines mental health as "a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community" (1)

Mental health includes our emotional, psychological, and social well-being. It affects how we think, feel and act as we cope with life events. It also helps determine how we handle stress, relate to others, and make choices. Mental health is important at every stage of life, from childhood and adolescence through adulthood.

2.2. Mental Illness

Mental illness is a condition that impacts person's thinking, feeling, mood, functioning and his or her ability to relate to others. Each person experiences illness differently, even people with the same diagnosis would have different experiences and perspectives towards the illness. Many people have mental health concerns from time to time. But a mental health concern becomes a mental illness when ongoing signs and symptoms cause frequent stress and affect the ability to function.

Mental illness can make a person miserable and can cause problems in the daily life, such as at work or in relationships. In most cases, symptoms can be managed with a combination of medications, social support and counselling (psychotherapy).

2.2.1. Types of Mental Illnesses

There are many different types of mentalhealth problems, just as there are many types of physical illness. Some of the defining characteristics of a mental health problems are:

- it is a recognized, medically diagnosable illness;
- it can cause significant cognitive, affective, or relational impairment;
- it results from biological, psychological and social factors;
- It can be managed using physical disease approaches (i.e. prevention, diagnosis, treatment and rehabilitation).

Some common types of mental illness are:

- **Mood disorders (affective disorders):** Depression, mania and bipolar
- **Anxiety disorders:** Generalized anxiety disorder, post-traumatic stress disorder, obsessive-compulsive disorder, panic disorder
- **Psychotic disorders:** schizophrenia
- **Concurrent disorders:** addictions and substance abuse
- **Personality disorders:** antisocial personality disorder, obsessive-compulsive personality disorder

2.2.2. Causes of Mental Illness

Most mental health professionals believe that there are a variety of contributing factors to the onset of a mental illness. Studies have found that there are physical, social, environmental and psychological causes for mental illness.

Biological and Physical Causes

Each individual's own genetic make-up can contribute to being at risk of developing a mental illness and traumas to the brain (via head-injury) can also sometimes lead to changes in personality and in some cases 'trigger' symptoms of an illness. Misuse of substances (such as alcohol or drugs) and deficiencies of certain vitamins and minerals in an individual's diet can also play a part. Physical health problems such as high or low blood pressure (B.P), diabetes, HIV and AIDS and other chronic diseases can also cause mental health problems as living with chronic illness can be very stressful (2).

Social and Environmental Causes

The living conditions along with family and community support networks can play a part along with employment status and work stresses. Living in poverty or social isolation, being unemployed or highly stressed in workplace can all put pressure on an individual's mental health.

Psychological Factors

The past or current traumatic experiences such as abuse, bereavement or divorce strongly influence an individual's mental and emotional state and if appropriate coping strategies are not used to address these experiences, they can in turn have a negative impact on individual's mental health.

Family History

The heredity can play some part in the development of some forms of mental illness. However, like with many physical health conditions (such as Heart Disease or Diabetes) the fact that a family member has experienced a mental health problem does not mean that all other genetic family members will experience the same condition. As with physical health conditions, the other factors shown above play a significant part for the onset of mental illness.

2.2.3. Symptoms of Mental Illness

The symptoms of mental disorders can produce a negative effect on the lives of individuals, families and society as a whole.

We cannot always tell just by looking at a person whether or not he/she has a mental disorder. The symptoms of mental disorders can be physical or psychological.

1. **Physical symptoms** are those that involve the physical functioning of the body e.g. aches and pains, weakness, tiredness, sleep disturbance, and increased or decreased appetite.

2. **Psychological symptoms** are those that involve the mental functioning of the body. It includes problems in understanding, concentrating, memory, and judgment

(decision-making), being aggressive, increased or decreased talking, withdrawal from family and friends; self-harm e.g. cutting the skin, and attempting suicide.

2.3. Models of Treatment

1. **Biomedical Model**

   Biomedical Model focuses on the physical or biological aspects and excludes psychological, environmental and social factors in an attempt to understand a person's medical illness or disorder. It focuses on physical processes that affect health, such as the biochemistry, physiology, and pathology of a condition. Most health care professionals do not first ask for a psychological or social history of a patient; instead, they tend to analyse and look for biophysical or genetic malfunctions (3).

2. **Psychological Model**

   Psychological Model focuses on the behaviour, cognition, and emotion and seeks to explain the mental processes and behaviour of individuals. It is commonly defined as the science of behaviour and mental processes (4). This treatment model therefore emphasizes psychological processes such as cognition, behaviour, emotions that are influenced by various social and experiential factors and therefore strives to “correct” these disruptive processes (3).

3. **Psychosocial Model**

   According to the Inter Agency Standing Committee (IASC), the term psychosocial denotes the inter-connection between psychological and social processes, and the fact that each continually interacts with and influences the other experiences (5). Psychosocial, thus emphasizes the close connection and interaction between psychological aspects of a person’s experiences and his/her experiences of wider socio-cultural aspects of the surrounding environment. Psychosocial support includes care and

support offered by friends, neighbours, caregivers, family members, teachers, health workers, and community members on a daily basis but also extends to care and support offered by specialised psychological and social services to enhance a person's ability to cope in their own context and to achieve personal and social well-being (6).

4. **Traditional/Spiritual Model**

In many traditional belief systems, mental health problems are perceived to be a result of angry ancestors or caused by bewitchment. The traditional healers and religious advisors are viewed as having expertise in these areas. Usually, there is a spiritual belief that there are good and bad forces in the world and that suffering are caused by the bad forces. In traditional societies, it is believed that suffering occurs because of sin or related concept of immoral behaviour that leads to some form of badness or contamination (7).

Lesson Plan: Session 3

Situation of Mental Health in Nepal

Total time: 1 hour 30 minutes

Objective: The participants will be able to;

- Describe the situation of mental health globally
- Delineate mental health situation in Nepal

SN	Topic	Activities	Methods	Materials & Resources	Duration	Facilitator
1	Introduction to global mental health situation and context	• Inform the participants about the objectives of the session • With the use of multimedia presentation, briefly describe: - global impact of disease of Mental Neurological and Substance use (MNS) disorders - changing trends of service delivery from hospital based care to community based care - Task shifting model	Presentation	Multimedia	20 Minutes	
2	Introduction to mental health situation in Nepal	• Show the documentary "Search for light" produced by Nepal Mental Health Foundation • Discuss what they saw/felt/learned from the documentary. Ask probing questions such as: - What do you think are the	Documentary, Discussion	Multimedia	35 Minutes	

		major barriers to mental health service delivery in Nepal? - Who do you think are the major stakeholders in the field of mental health in Nepal? - In your opinion, how are people with mental health problems treated in Nepal?				
3		• Through multimedia presentation, briefly describe: - Impact of MNS disorder in Nepal - Mental health resources available in Nepal - Prioritization of mental health by government (in policies and financing)	Presentation	Multimedia	30 mins	
4	Summary and conclusion	• Summarize the main points of the session and conclude the session			5 Minutes	

Reading Material: Session 3

Situation of Mental Health in Nepal

3.1. Introduction to Mental Health in Global Context

3.1.1. Global Impact of Disease

Mental illness accounts for nearly 7.4% of the global impact of disease and is the 5th leading contributor of the impact (8). Within mental, neurological, and substance use disorders, mental disorders accounted for the highest proportion of DALYs (56.7%), followed by neurological disorders (28.6%) and substance use disorders (14.7%) (9). Although the peak impact of mental, neurological, and substance use disorders is found in young adults, there is, unlike many chronic diseases, a significant impact in children and younger adolescents. Mental, neurological, and substance use disorders contribute to a significant proportion of the global impact of disease and will continue to do so as the shift in impact from communicable to non-communicable diseases continues. Health systems worldwide need to respond to this rising impact by implementing proven, cost-effective interventions; where these are limited, it will be important to support the research necessary to develop better prevention and treatment options.

3.1.2. Changing Trends of Service Delivery from Hospital based Care to Community based Care

The service delivery trends around the world are changing and many countries are focusing on community based care as an approach to deliver care closer to home and to improve patient outcome. Community based health care are vital part of the care continuum, ranging from highly professional services to simple forms of non-professional and voluntary support in homes. (10)

The emphasis is that more general health concerns could be effectively addressed in community, leaving hospitals to provide specialized care.

3.1.3. Task Shifting Model

Task shifting is a low-cost solution to tackling gaps in health services in the developing world, for example those in HIV and mental health treatment. The WHO defines it as "the rational redistribution of tasks among health workforce teams" where specific tasks of health specialists are re-allocated when appropriate to less specialized health workers after providing appropriate trainings and supervisions (11).

By reorganizing the workforce in this way, task shifting presents a viable solution for improving health care coverage by making more efficient use of the human resources already available and by quickly increasing capacity while training and retention programs are expanded (12).

3.2. Mental Health in Nepal's Context

3.2.1. Situation of Mental Health in Nepal

In Nepal, very few studies have been conducted on mental health among the general population and such studies lack national coverage so it is difficult to make real estimates of impact of MNS disorder in Nepal. However, small scale studies conducted with particular groups or in certain geographical regions show a higher impact of MNS disorder. For example, a recent study has shown suicide as the first leading cause of death among women of reproductive age in Nepal (13). Similarly, a study conducted in three conflict affected districts of Nepal (Dang, Chitwan and Tanahu) found that 27.5 % of the respondents met threshold for depression, 22.9 % for anxiety, and 9.6 % for PTSD (14).

Despite higher impact of MNS disorder less than 1% of all health expenditures are directed towards mental health (15). The country has a national mental health policy but its provisions have not been fully implemented. Despite these shortcomings, there is a good network within the general health service system where mental health can be integrated. There is a gradual increase in awareness of mental health in the general population and the number of people seeking treatment in the mental health institution is increasing. In the essential drug list psychotropic medicines are included up to the primary health center. Some private medical colleges and NGOs are providing psychiatric services. There is a good family system, which takes

responsibility for their sick family members at home. **3.2.2. Mental Health Resources Available in Nepal**

Mental health resources are scarce with no formal mental health care in rural areas where more than 85% of the total population resides. There is one mental hospital in the country which has a total of 50 beds. Only 7 district hospitals out of 75 provide mental health services; provision of psychotropic medications for epilepsy is the only form of mental health care in the public health care system; and there are less than 60 psychiatrists in the country (25 of whom work outside the country) (17). There are 25 outpatient mental health facilities available in the country. Similarly, there are 3 days treatment facilities and 400 psychiatric inpatient units (i.e. general hospitals and teaching hospitals) available in the country. The availability of 0.18 psychiatrists, 0.25 nurses, 0.04 psychologists per 100,000 population (15) indicates to the limited mental health human resources capacity and calls for policy priority on mental health training and capacity building

3.2.3. Prioritization of Mental Health by the Government (in policies and financing)

Mental health has not yet been the priority for Nepal government. Despite formulating the National Mental Health Policy in 1996, the government has not allocated sufficient budget to mental health nor it has implemented the key components mentioned in the policy.The policy of 1996 aims : (a) to ensure the availability and accessibility of minimum mental health services for all the population of Nepal; (b) to prepare human resources in the area of mental health; (c) to protect the fundamental human rights of the mentally ill; and (d) to improve awareness about mental health. There is no human right review body to inspect mental health facilities and impose sanctions on those facilities that persistently violate patients' rights (16).

Although exact values are unavailable, mental health expenditures comprise 0.7% of the total health budget. These expenditures are borne by many government institutions like National Health Training Centre(NHTC), National Center for AIDS and STD Control (NCASC), the Management Division, Family Health Division and the Mental Hospital itself. In terms of affordability of mental health services, a negligible portion of the population has free access to

essential psychotropic medicines; however, there is no specific data on how many people are receiving medicines for free (16).

Lesson Plan: Session 4

International and National Legal Provisions

Total time: 1 hour 45 minutes

Objective: The participants will be able to;

- State the provisions of UNCRPD and importance of ratification of UNCRPD
- Critically analyse the shortcomings of Nepal's legal provisions
- List the benefits provided by Nepal government for people with mental health problems

SN	Topic	Activities	Methods	Materials & Resources	Duration	Facilitator
1	Conceptualizing mental health as human rights: national and international provisions for protection of rights of persons with mental illness	• Start with a case study of human rights violation of persons with mental health problems. Just present the case description without saying violation and then discuss with participants what they understand by human rights and what aspects of human rights have been violated in this case example. Brainstorm the meaning and understanding of human rights and its importance. Provide some examples of basic human rights protection provisions (right to privacy, freedom of thought and speech, life and dignity, health, education etc). • Draw a picture of tree on newsprint paper. Explain that	Brainstorming, discussion, participatory method, presentation	Meta-card, markers, newsprint paper, multimedia, video interview	1 hour	

		the tree represents the human rights of people with mental health problems and caregivers. • Describe what kind of fruits the participants hope is borne by the tree or what rights do they hope are protected for people with mental health problems and caregivers (for example, right to dignity, non-discrimination, legal capacity, freedom of expression, freedom from torture and forced treatment, freedom from sexual and other violence and abuse, freedom to compete equally in government positions, confidentiality, access to information etc.) Write the response on meta-cards and stick them on the branches of tree as fruits. The facilitator can discuss if these rights are protected in Nepal.[1] • On the next step, ask the participants what helps to achieve these fruits or what instruments help them secure these rights. Ask if they know of				

[1] Note to facilitator: In case of non-literate groups, rather than asking the participants to write on a meta-card, the facilitator should ask them to give their response verbally while facilitator writes them down on meta-cards.

		any national or international treaties and policies in place to secure their rights. • Write these international (UNCRPD and other international human rights instruments relevant for mental health such as CEDAW, ICCESR and CRC) and national (civil code, mental health policy, health act, NHSSP, NCD multi stakeholder action plans) instruments that secure rights of persons with mental health problems in meta-cards and stick them on the roots of the tree. • With special focus on UNCRPD, explain what provisions are in place in the instruments and why they are important with the help of powerpoint presentations.[2] • Similarly, discuss what provisions are in place in the national policies and plans for persons with mental health problems and why they are important with the help of power point presentations.				

[2] For non-literate groups, short video interview of experts describing UNCRPD and its general principle can be shown.

		• Next, discuss which legal provisions in Nepal undermine the rights of persons with mental health problems. Write them on meta-cards and stick them on the soil around the roots of the tree. • Explain how these provisions acts as bugs and insects that can destroy the tree i.e. violate the rights of persons with mental health problems. • Summarize the points with the help of a song/ poems from the participants /trainers				
3	Benefits and services available	• Divide the participants into 2-3 groups. Provide each group map of their district. Ask them to stick a small card with name of mental health resources available in the district that they know of. Provide 15 minutes for this. • Ask each group to present their map (5 minutes for each group). • At the end of the presentations, the facilitator can add other government, non-government, and private mental health resources available on their maps prepared by the	Community mapping method, brainstorming, discussion	Maps of the district, cards, markers, pins/gluestick	40 minutes	

		participants. • Brainstorm with the participants what benefits are made available by the government for persons with mental illness.				
4	Summary and conclusion	• Summarize the main points of the session and conclude the session			5 Minutes	

Reading Material: Session 4

International and National Legal Provisions

Total time: 1 hour 45 minutes

4.1. Conceptualizing Mental Health as Human Rights: National and International Provisions for Protection of Rights of Persons with Mental Illness

4.1.2. Human Rights

Human rights are the fundamental rights that humans have by the fact of being human, and that are neither created nor can be abrogated by any government. According to The United Nations Universal Declaration of Human rights, human rights are “rights inherent to all human beings, whatever our nationality, place of residence, sex, national or ethnic origin, color, religion, language, or any other status. We are all equally entitled to our human rights without discrimination. These rights are all interrelated, interdependent and indivisible." (18)

Universal human rights are often expressed and guaranteed by law, in the forms of treaties and customary international legal provisions. International human rights law lays down obligations of Governments to act in certain ways or to refrain from certain acts, in order to promote and protect human rights and fundamental freedoms of individuals or groups.

Supported by several international conventions and treaties (such as the United Nation’s Universal Declaration of Human Rights in 1948), human rights include cultural, economic and political rights such as rights to life, liberty, education, and equality before law, and rights of association, belief, free speech, information, religion, movement and nationality.

The following are some of the most important characteristics of human rights:

- Human rights are founded on respect for the dignity and worth of each person;
- Human rights are universal, meaning that they are applied equally and without discrimination to all people;
- Human rights are inalienable, in that no one can have his or her human rights taken away; they can be limited in specific situations (for example, the right to liberty can be restricted if a person is found guilty of a crime by a court of law);
- Human rights are indivisible, interrelated and interdependent, for the reason that it is insufficient to respect some human rights and not others. In practice, the violation of one right will often affect respect for several other rights.
- All human rights should therefore be seen as having equal importance and of being equally essential to respect for the dignity and worth of every person.

According to WHO (19), rights of users of mental health services are:

i. Confidentiality: This right states that the legislation of particular country must ensure patients' right to confidentiality. Legislation should specify that all information obtained in a clinical context (i.e. in the context of care and treatment in any setting) is confidential and that all concerned have a responsibility to maintain confidentiality.
ii. Access to information: This right states that legislation should ensure that people with mental disorders have the right to free and full access to their clinical records.
iii. Rights and conditions in mental health facilities: This right states that legislation should guarantee patients in mental health facilities protection from cruel, inhuman and degrading treatment.
iv. Notice of rights: This states that legislation should include a provision for informing patients of their rights at the earliest possible time, when interacting with mental health services. Notifying them of their rights should take place within the shortest delay possible.

4.2. Key International Human Rights Instruments Related to the Rights of People with Mental Disorders

The Universal Declaration of Human Rights (1948) (18), along with the International Covenant on Civil and Political Rights (ICCPR, 1966) and the International Covenant on Economic, Social and Cultural Rights (ICESCR, 1966), together make up what is known as the "International Bill of Rights" which also talk about the rights of people with mental illness. Article 1 of the Universal Declaration of Human Rights, adopted by the United Nations in 1948, provides that all people are free and equal in rights and dignity. Thus people with mental disorders are also entitled to the enjoyment and protection of their fundamental human rights.

The right to health is also recognized in other international conventions, such as Article 5(e)(iv) of the International Convention on the Elimination of All Forms of Racial Discrimination of 1965, Articles 11.1(f) and 12 of the Convention on the Elimination of All Forms of Discrimination against Women of 1979, and Article 24 of the Convention on the Rights of the Child of 1989.

The legally binding UN Convention on the Rights of the Child contains human rights provisions specifically relevant to children and adolescents. A number of its articles are specifically relevant to mental health: Article 23 recognizes that children with mental or physical disabilities have the right to enjoy a full and decent life in conditions that ensure dignity, promote self-reliance and facilitate the child's active participation in the community. Article 25 recognizes the right to periodic review of treatment provided to children who are placed in institutions for the care, protection or treatment of physical or mental health. Article 27 recognizes the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development. Article 32 recognizes the right of children to be protected from performing any work that is likely to be hazardous or to interfere with their education, or to be harmful to their health or physical, mental spiritual, moral or social development.

The most popular international human rights instrument that talks about rights of people with mental illness is the United Nation's Conventions on the Rights of Persons with Disabilities (UNCRPD) (20). The major focus areas of UNCRPD are:

i. Access to justice (Article 13 UN CRPD): This article ensures effective access to justice for persons with Disabilities on an equal basis with others, for this the article also includes provision of training of stakeholders (police, prison staffs) for providing effective justice.
ii. Accessibility (Art 9 UN CRPD): this article says that "the state should take measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas".
iii. Independent living (Article 19 UN CRPD): this article recognizes "the equal right of all persons with disabilities to live in the community, with choices equal to others. It also ensures to take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community."
iv. Involuntary treatment and involuntary placement (Articles 14 and 15 UN CRPD): This article states that "respective country would protect the right to liberty and security of the person with disabilities and would also take effective measures to protect them from inhuman or degrading treatment".
v. Legal capacity (Article 12 UN CRPD): This article states that those countries who have signed UNCRPD" should recognize and ensure that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life."
vi. Political participation (Article 29 UN CRPD): This article states that "persons with disabilities should get equal political rights and the opportunity to enjoy them on an equal basis with others."

4.3. National Laws Relevant to Mental Health

The Nepali Civil Code 1963/64 assumes state responsibility for treatment of people with mental health problems(21). The legal definition of mental illness was not clarified, but the

language of the legislation refers to someone with a broken mind or madness or insane. Some of the provisions mentioned in the Civil Code are:

- Part-2 Chapter-1 on court proceedings, states that in case of minor (below the age of 16), there should be presence of guardian or heir or a witness in the court proceedings if the person is mentally ill.

- Chapter- 2 on punishment number 1, states that if a person who commits an offense without knowing the consequences and is mentally ill, the act committed by the person is not liable to any kind of punishment. But if the person has committed the offense under the pursuance of others, the ones who have provoked to commit the offence would be liable for the punishment.

- Chapter- 12 on husband and wife, states that if the husband or the wife have lived separately for three years or more or led to his/her physical or mental suffering, in such situation, the conjugal relation may be dissolved with the consent of both the parties.

- Chapter - 15 on adoption, states that if the adopted son/daughter fails to look after the adoptive parents, giving physical and mental torture to them, in such situation, such adoptive parents may revoke the adoption.

- Chapter - 17 on marriage, states that if the marriage is concluded with a male or a female who is insane or epileptic, under the false representation that he/she is normal, such a marriage shall be void if the spouse does not accept the marriage

The National Health Policy of 1991 (22) has stipulated mental health promotion programs specially in child mental health, community mental health and psychosocial support.

Similarly, the national mental health policy of 1996 recommends the integration of mental health into primary health care (23). It aimed to ensure the availability and accessibility of minimum mental health services for all the population of Nepal by the year 2000 but in practice it has not yet happened. The policy had also laid down various strategies like establishing a

Division of Mental Health in the Ministry of Health/Department of Health Services and the mental health unit in the Regional Directorates of Health. However, as of now the strategies have not been implemented.

Nepal Health Sector Program II (2010-2015) (24) has stated that mental health services will be strengthened, health workers will be trained for case detection and referral, and there will be availability of basic psychotropic drugs and anti- epileptic medicines at the Health Post level. Though some initiatives have been taken from the government's side, it still lacks proper implementation. Likewise, NHSP II had provision to appoint a focal point for mental health within the Ministry of Health and Population (MoHP). However, currently no such focal point exists.

Similarly, the Non Communicable Disease Multi-Stakeholder Action Plan (2014-2020) (25) mentions the establishment of a mental health unit but there is no responsible unit for mental health to govern the mental health system fully and responsibly.

Likewise, the Local Self-Government Act, 1999 (26) imposes duty on VDCs to keep record of children with disabilities. Social Welfare Act, 1992 (27) focuses the duty of the government to work for the protection, promotion and welfare of person with disabilities. Special education should be provided to "blind, deaf, dumb or the children who are physically or mentally disabled." Though there are some good provisions but in reality these provisions are never applied and rights are violated and breached. Health policy 2014 (28) recognizes the need to increase state's investment to cover all health care expenses of disabled people, including psychosocial disability.

4.4. Benefits and services available for mental health in Nepal

1. Government Services: For patients with mental health problems, Mental hospital, Lagankhel has got has total 50 psychiatric beds, Tribhuwan University Teaching Hospital has 12 psychiatric beds and 10 beds for drug addiction and there is provision of one psychiatrist in every Zonal Hospital

2. Disability allowance for people with mental health problems. Allocation of red, blue, white or yellow card (based on the severity of disability status) enables them to get concessions in education, health and transportation. despite these provisions people with mental health problems have been facing difficulties while getting the card as well as services.

Box Number: 1 Case Study: Experience of a person with mental health problem for getting disability card

Case Study

I took psychosocial disability identity card in the year 2067 B.S.(2010/2011A.D) I had to complete several processes to get that card. Firstly, I had to get a recommendation letter from Mental Hospital, Lagankhel, Lalitpur regarding my treatment history and the medicines that I was taking for my illness. I also had to get recommendation from ward office (wada karyalaya) stating that I am the resident of that place. I then submitted an application to Women Development Committee requesting to grant me the disability card. They reviewed my application and supporting documents and I got a white colored identity card from there in which it was mentioned intellectual disability. I was not happy with the category of "intellectual disability" so I went back to them and mentioned that I am not a person with intellectual disability but with psychosocial disability. They then informed me that in the clarification section, psychosocial is mentioned too. Thus, it is clear from this that the related institutions are not aware about the different types of disability mentioned by UNCRPD. I also discussed about it with the personnel there saying how they can term me as a person with disability. They then told me that since I have to keep taking medicine for a long time, I will not be able to carry on my daily activities, and that my mind will not be able to function well so even when it is not physically visible it can be termed as disability. I also faced lots of challenges after receiving the identity card. It is mentioned that I can get services for free in government colleges, government hospitals and I can get discount in transportation but since our disability is not physically evident, I have been questioned many times about it, I have been caught in discussion regarding this. In addition, I feel like there is a low chance of getting selected for public service commission when one has this identity card of disability. Moreover, I haven't got any employment opportunities on the basis of my identity card. So rather than terming it as a service, it has become a stigma. I think it is quite uneasy to use the identification card of psychosocial disability than of other types of disability as I have had to discuss about it in different service oriented institutions to seek services. On positive note, due to this disability card, I have been able to get admission in Nepal Law Campus and get services from Bir hospital. So, I encourage people with mental health problems to take disability card and receive the benefits that are provisioned in government policies.

Other Services:

There are approximately 50 psychiatric clinics and 12 psychological counselling centres, besides these, medical colleges are also providing psychiatric services. Some NGOs like TPO (Transcultural Psychosocial Organization) Nepal, CMC (Centre for Mental Health and Counselling), CIVICT (Centre for Victims of Torture Nepal), KOSHISH Mental Health Self-Help Organization, Women's Group for Disability Rights are providing mental health and psychosocial services.

Lesson Plan: Session 5

Group Activity: Developing a Plan of Action (on what the people with mental health problems and care givers can do practically in their community)

Total time: 1 Hour

Objective: The participants will be able to;

- List the activities and the ways on what they as people with mental health problems and caregivers can do practically in their community based on what they have learned in previous sessions

SN	Topic	Activities	Methods	Materials & Resources	Duration	Facilitator
1	Group activity	• Divide the participants into 2-3 groups. • Tell the groups that they are now service user/caregiver advocates in their community. Ask them how they will utilize the knowledge they have gained on the day- mainly related to legal provisions, services and benefits for persons with mental health problems in their community. • Ask them to come up with activity plan and present them in the group (give some ideas if needed such as street dramas, community awareness programs etc.)	Group work	Newsprints, markers	55 Minutes	
2	Summary and conclusion	• Summarize the main points of the session and conclude the session			5 Minutes	

Day 2

Lesson Plan: Session 6

Introduction to People with Mental Health Problem and Caregiver Involvement in Mental Health System Strengthening

Total time: 1 hour 30 minutes

Objectives: The participants will be able to;

- Describe the meaning of service user and care giver involvement
- Define the levels of participation
- List the benefits and challenges of service user/caregiver involvement

SN	Topic	Activities	Methods	Materials & Resources	Duration	Facilitator
1	Introduction to service user/caregiver	• Inform the participants about the objectives of the session. • Ask participants what they understand by service user/caregiver and note down the views of participants. • Briefly describe the meaning of service user and care giver. • Through the use of multimedia, briefly describe the background for people with mental health problems and caregivers' movement globally. • Explain how/in what ways people with mental health problems and caregivers are	Brainstorming, discussion, presentation	board/newsprint paper, markers, multimedia	55 minutes	

		being involved in other countries. • Discuss the benefits and challenges of user/caregiver involvement. • Also, discuss the changing names given to people with mental health problems throughout the movement. Ask what they think is appropriate term to indicate service user.				
2	Levels of service user/caregiver Involvement	• Brainstorm what the participants understand by involvement of people with mental health problems/caregivers. • Discuss their understanding and summarize. • Through power point presentation (or picture presentation for non-literate group), briefly explain various levels of service user/caregiver involvement and ways of involvement (based on route map on service user involvement).	Brainstorming, discussion, presentation	board/newsprint paper, markers, multimedia	30 minutes	
3	Summary and conclusion	• Summarize the main points of the session and conclude the session			5 Minutes	

Reading Material: Session 6

Introduction to People with Mental Health Problems and Caregiver Involvement in Mental Health System Strengthening

Total time: 1 hour 30 minutes

6.1. Meaning of People with Mental Health Problem and Caregiver Involvement

The term "service user" is used as a generic description of the people who use mental health services. Care giver is an individual, such as family member or guardian, who takes care of a person with mental health problems.

Service user involvement is about making sure that mental health services, organizations and policies are led and shaped by the people who experienced mental illness and their caregivers.The people with mental health problems and caregivers are experts by experience. As the wider benefits of inclusion have become apparent and recognized, there is a greater need for active inclusion of the perspectives of people with mental health problems and their caregivers collectively in the design, commissioning, delivery and evaluation of services, as well as in policy development locally and nationally.

6.2. People with Mental Health Problems and Caregiver Movement Globally

The development and growth of service user movement has led to the transition in the treatment from institutional care to community based care. Service user organizations began to develop in North America and Western Europe in the 1970s and 1980s. By the early years of 21st century; such organizations were established in many countries of the less developed world as well. The basic argument of these organizations was that mental illness was a social and political construct and that people needed basic legal and human rights protections (29). As these organizations developed, they called for active participation by people who received services and their caregivers in the decisions that affected their lives (30).

In recent years, this strategy of involving service user and their caregivers has been promoted in different countries. Several Organizations of Economic Cooperation and Development (OECD) countries have formalized approaches to service user involvement. For example, both Canada and Denmark have used service user involvement to develop health policy, while case studies from Belgium, the Czech Republic, the USA, Hungary, France, and Korea discuss service user involvement in policy making and implementation in other fields.

Over the past 30 years a wide range of developing countries have successfully developed a model of primary health care promoted by the WHO. This is based on the idea of 'essential health care based on practical, scientifically sound and socially acceptable methods and technology, made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain' (31).

6.3. Changing Names given to people with mental health problems and Caregivers throughout the Movement

The word 'Lunatic' was used for people with mental health problems and 'lunatic Asylums' was used to describe the place where these people resided until second half of 19th century since the word was socially and medically acceptable then . By the early 1900s, the term "lunatic" was dropped by medical authorities in many places thinking it as inappropriate to describe a person with mental health problems. Subsequently, the term "lunatic" disappeared from the mental health institutions' reports published at that time. Some lobbyist, lobbied for the term "hospital" instead of asylum to the place for seeking medical treatment. In many places, by 1907, places that were formerly called ''asylums'' were officially known as ''Hospitals for the Insane". People who were confined to these facilities were referred to as "inmates" that gradually changed into "patient". Then again, the term "mental hospital patient" was intended by some other advocates of mental health.

During early 1970s activists used words that were intended to cast off the stereotype of the passive mental patient incapable of doing anything for themselves, while also using language that wanted to convey a sense of fighting against oppression. (32).

After sometimes the term "patient" came to be increasingly rejected by some activists and began to use the term "consumer". While "patient" continued to be used by professionals, "consumer" became increasingly attractive in the consumer society of North America. The term consumer however encompasses all manner of "transactions" from retail shopping to people choosing medical services. Some mental health professionals connected psychiatric patient advocacy with "consumer rights". This change in the terminology turned to be a wakeup call to mental health professionals to reform the mental health system in the western countries. From the outset of its use, the term ‘‘consumer’’ was linked up with being part of a movement within mainstream psychiatry that wanted to be seen as incorporating the views of patients in their own treatment while also improving their ‘‘quality of services. After certain point of time the term "survivors" appeared in a few articles during 1980s pointing out that those people survived psychiatric abuses. The term, ‘‘psychiatric survivors’’ began to be used on a widespread basis in Canada during the late 1980s especially after the first national conference of activists was held in Montreal in November 1989. By this time, the National Association of Mental Patients in the United States had become the National Association of Psychiatric Survivors (32).

By the early 1990s, the terms, ‘‘consumer’’ and ‘‘survivor,’’ often joined, as in consumer/survivor, became more well-known forms of self-definition. Initially, psychiatric survivor was identified with an anti-psychiatry perspective, rejecting the concept of mental illness and wanting to replace psychiatry with survivor-run alternatives in the community. (32).‘‘Consumer,’’ on the other hand, is a term that connotes choice and autonomy in treatment, an early demand of anti-psychiatry activists, but with a significant difference—people who identify as consumers want to work for reforms from within psychiatry and accept the medical model of mental illness. There were also people who wanted to maintain bridges

with both sides and therefore identify as consumer/survivor, individuals who try to remain inclusive of the varied perspectives within each of these approaches while also acknowledging that this term itself was rejected by more than just a few people who identify with either one or the other(32). Thus, there was a diverse group of people who had different views on the terminologies. In spite of confusion of terms, the period since the early 1970s had witnessed the largest numbers of current and former psychiatric patients involved in the reshaping of language and attitudes on this topic than at any previous time in history(32). In addition to the terms already mentioned, the term ‘‘user’’ has been widely adopted in Britain as a form of self-definition among people who receive psychiatric services, but it has not caught on to any significant degree in North America(32).Certainly, the older terms have not disappeared. This is especially true of ‘‘patient,’’ which continues to be very widely used when describing someone who is receiving psychiatric treatment, including recipients of treatment themselves. Lunatic and crazy have long been considered insults by people who have been in mental health institutions in the 20th century, but in the last generation, a number of people have used these very words in their writings to show their opposition to psychiatry (32).

6.4. Levels of People with Mental Health Problem and Caregiver Involvement

Service user and caregiver involvement may take place in a number of ways appropriate to the individuals and the activity concerned. Examples of involvement include:

- Giving information and listening
- Consultation
- Shared decision making
- Working together

People with mental health problems should have the freedom and choice to participate in the design, delivery and review of mental health services in a range of ways. Historically, a ladder of participation has been used to describe the ways in which a service user may wish to become involved (33). This one-dimensional hierarchical approach to participation has been criticized,

but is still widely used and adapted. One such adaptation of service user involvement framework (34) is described below:

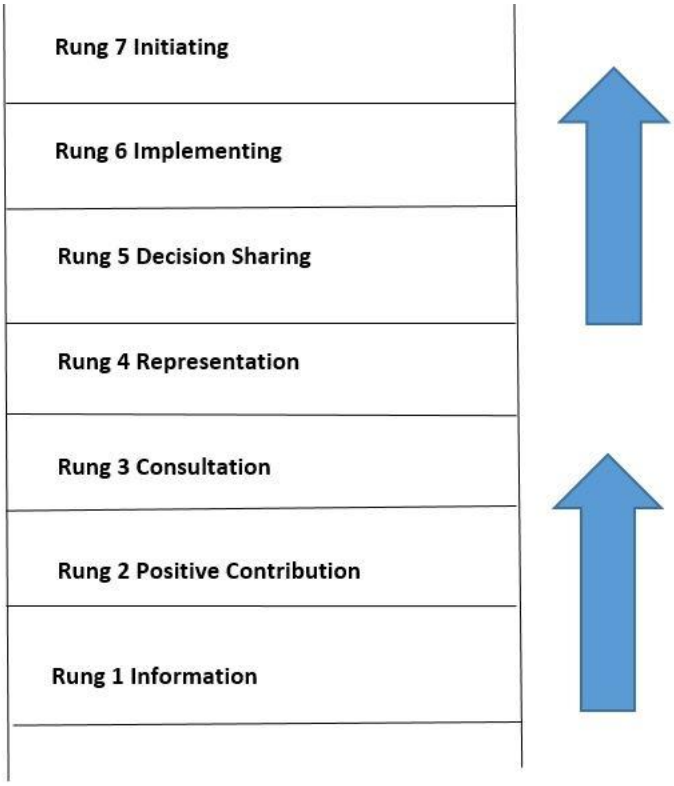

Figure: 'The Ladder of Participation'

Rung 1: Information

People with mental health problems are provided with information in forms of poster, leaflets or meetings, which is passively consumed by people with mental health problems. Service providers have control of the information and decide for people with mental health problems on what, when, and how information is shared.

Rung 2: Positive Contributions

Views and opinions of people with mental health problems are sought by the service providers, but the people with mental health problems are still clueless as to how the questions are asked or what happens to the information they provided. For example, the people with mental health

problem satisfaction survey provided by organizations or facilities, which are developed by staff members.

Rung 3: Consultation

People with mental health problems are consulted after service providers generate ideas. Key decisions are still taken by the service providers; however, they take into account the views of people with mental health problems. For example, the development of a new service or the development of new policy related to mental health.

Rung 4: Representation

Selected people with mental health problems represent the views of their peers on specific items; this might be through people with mental health problem's forums.

Rung 5: Decision Sharing

The decision making process is shared by service providers and people with mental health problems alike. This could include being involved in the recruitment of staff members within a project.

Rung 6: Implementing

"People with mental health problems are given responsibility for a project and its outcomes". An example of this could be people with mental health problems operating mobile mental health camp.

Rung 7: Initiating

All ideas are generated by people with mental health problems. People with mental health problems are solely involved in major decision making process. In this process, service providers are consulted but are not actively involved. For example, a people with mental health problem group, making decision on planning of programs for people with mental health problems.

People with mental health problems may choose to be involved at one level over another as per their personal strengths, circumstances or the nature or organization that they are in contact with. Policy makers and providers should strive to provide opportunities for involvement at all seven levels of the ladder wherever possible.

6.5. An Example of People with Mental Health Problem Involvement in Research: A Route Map (35)

Route 1: People with Mental Health Problem Involvement in Research Management

Why involve people with mental health problems and their care givers?

If we want the research to be more beneficial to the people with mental health problems and their care givers, we have to involve them in research from developing questionnaire to dissemination of study findings. The people with mental health problems and their care givers , who have been involved in research can be the most powerful advocates, promoting understanding among other people with mental health problems and acting as a bridge between people with mental health problems community and other governmental and non-governmental stakeholders.

Why involve people with mental health problems and their care givers in developing research strategy?

Research strategy set outs the objectives and priorities for research over a period of years.

Involving people with mental health problems and their care givers in developing research strategy would be helpful to develop relevant tools and techniques for collecting data. It would also provide people with mental health problems and their care givers the opportunity to have their voices heard in the issues of their concern.

Why involve people with mental health problems and their care givers in setting research priorities?

Research priorities can be different for people with mental health problems, their care givers, clinicians and researchers. It is important to ensure maximum involvement and participation of people with mental health problems in decision making process related to research priority setting, if we have to reflect the interests of people with mental health problems and their care givers in research.

Why involve people with mental health problems and their care givers in reviewing research funding applications?

If we involve people with mental health problems and their care givers as reviewers it would help bring their perspectives in the review process. Incorporating their views in the review process would help identify funding applications that would benefit people with mental health problems and their care givers.

Why involve people with mental health problems and their care givers in making funding decisions?

People with mental health problems and their care givers may take on more of non-executive role, ensuring there is transparency and public accountability in the process of making funding decisions. If they are involved it would make them and other stakeholders more accountable in the research project.

Why involve people with mental health problems and their care givers in monitoring and evaluating research projects?

There are various ways of involving people with mental health problems and their care givers in monitoring and evaluating research projects. One of the ways is to involve people with mental health problems and their care givers in site visits during the course of research. This helps in the implementation of research. They can contribute by providing their perspective to the evaluation process to ensure that the issues of importance to people with mental health problems were taken into account.

Why involve people with mental health problems and their care givers in dissemination of research findings?

Involving people with mental health problems and their care givers in the dissemination of research findings might help to reach the local audiences more effectively and efficiently. The information given by them would be more impactful to the audiences.

Route 2 the infrastructure to support people with mental health problem and their care givers involvement

Why is it important to plan for user involvement and their care givers?

It is important to plan for user involvement and their care givers because it would help to envisioning the results that the organization wants to achieve. It would also help in determining the steps that should be taken in order to achieve the set goal.

Why is it important to get buy-in from senior people?

It is important to get the support of senior people of the organization in order to get the approval for allocating resources for user involvement. Senior people may also help to convince other supporting staffs for the involvement of service user. This would help others to see involvement of people with mental health problems as a priority.

Why develop new policies and procedures?

It is important to develop new policies and procedures to help clarify expectations and responsibilities of all stakeholders and also to deal will the difficult situation.

Why is it important for recruiting and retaining people with mental health problem and their care givers?

Recruiting and retaining people with mental health problems and their care givers is important for involvement. For recruiting people with mental health problems and their care givers, it is important to develop a role description and person specification of people with mental health problems and their care givers in the organization since it would enable them s to make an informed decision about whether they want to get involved.

Why Train people with mental health problems and their care givers?

It is important to train people with mental health problems and their care givers because it would enhance their skills, knowledge and capabilities for involving in research.

Why provide support to people with mental health problems and their care givers?

Providing support to people with mental health problems and their care givers would make them feel valued and heard for their needs. It would enable them to be involved in research.

Why train and support staffs?

It is important to train and support staffs of the organization for involving people with mental health problems. Training staffs would enable them help people with mental health problems to get involved more easily. If they are well trained, they can help support people with mental health problems emotionally.

Why evaluate people with mental health problems and their care givers involvement?

Evaluating people with mental health problem's involvement and their care givers within the organization helps to identify what works and what does not work, share learning, improve the planning of future projects and also provide another mechanism for their involvement.

Route 3 Promoting and supporting people with mental health problem and their care givers involvement in research projects

Why help with recruitment to research?

Helping people with mental health problems in recruitment to research would help people with mental health problems to find research projects to take part in, it would enable researches to gain credibility from research funding organization since they have involved people with mental health problems in research, it would also ensure that the research reflects the interests of people with mental health problems.

Involving people with mental health problems in research would increase the relevance of research; it would improve the quality of data and its interpretation, it would also ensure that the findings of the research would be used to make a difference to people with mental health problems' lives.

Similarly, people with mental health problems can also be involved in policy making and planning of issues related to mental health.

6.6. Benefits and Challenges of People with Mental Health Problem and Caregiver Involvement

People with Mental Health Problem and their care giver's involvement is the active participation of a person with lived experience of mental distress in shaping his/her personal health plan, based on his/her knowledge of what works best for him/her

6.6.1. The Benefits of Involving People with mental health problems:

- The meaningful involvement of people with mental health problems offers benefits to both individuals and the community at a strategic level.
- People with mental health problems are recognized as experts in their experience and often have a good knowledge of services and how the system works.

- People with mental health problems bring their own perspective about treatment and care. This can help prompt service providers and practitioners to re-evaluate the provision of services, challenges and traditional assumptions and highlight key priorities they would like to see addressed.
- Decisions are more likely to be seen as positive by those who have had an opportunity to contribute to making them. Sharing the agenda promotes constructive working relationships.
- If the people with mental health problems are involved in the research, the services will be better designed, new perspectives on well-researched issues will be highlighted and many aspects of social exclusion faced by many people with mental health problems will be addressed.
- Involvement has a positive impact upon service user and mental health well-being and also has benefits for service planner, providers and society in general. These include the delivery of more effective services and better value for money through less waste on ineffective interventions.
- Implementing evidence based practice which shows that involving people in planning and developing health services contributes to effective changes in the provision of services across a range of different settings.

6.6.2. Challenges of involvement of people with mental health problems and their care givers in mental health policy development, program design, service delivery and monitoring and evaluation (Findings from a study conducted by TPO Nepal in 2014).

- Lack of awareness, information, and education could be a dominant factor that could hinder their involvement in system strengthening processes and could trigger other factors such as lack of confidence and capacity limitation.
- Lack of education, awareness, poor economic condition, and being from rural setting could lower their confidence and increase their feeling of inferiority that might hinder their participation in policymaking and other system strengthening process.

- Due to the presence of stigma in the community, people with mental illness and their caregivers fear to come out and identify themselves as people with mental disability. Nevertheless, without an identity for people with mental health problems such as 'disabled', it is difficult for them to receive disability benefits and compete in government level positions.
- Lack of access to involvement in system strengthening processes is a barrier to the people with mental health problems and their care givers living in rural area since such processes take place in big cities.
- Poor economic condition of people with mental health problems could be a barrier to involvement since their first priority would be to meet the basic need of the family and their focus would be on free treatments and medicines, and income generating activities, rather than involvement in mental health system strengthening process.
- The people with mental health problems who had participated in the policy making process had mentioned that in the past, the draft policies were made by certain group of people, mainly comprising of psychiatrists and policy makers in 'great secrecy'. There was token participation of people with mental health problems .People with mental health problems were not directly involved in drafting the policy and the policy that was drafted was not released by the government.
- Instability of the government, and frequent transfer of government staff hinders the policy making process and the relationship built between people with mental health problems and government. The unstable government leads to frequent changes in the bureaucratic system of the ministry and slows down the attempts made by people with mental health problems and other stakeholders to strengthen mental health system in coordination with the government.
- There is strong dominance of psychiatry and biomedical approach in the field of mental health in Nepal, which prevents their involvement in mental health system strengthening process.

Lesson Plan: Session 7

People with Mental Health Problems and Caregiver Involvement in Health System Strengthening Process in Nepal

Total time: 2 hours

Objectives: The participants will be able to;

- Describe the scenario of service user/caregiver involvement in Nepal
- List sustainable ways of service user/caregiver involvement

SN	Topic	Activities	Methods	Material s & Resources	Duration	Facilitator
1	Involvement of service user/caregiver in Nepal	• Inform the participants about the objectives of the session. • Ask participants if they have any experiences of involvement in policymaking process and research. If they have, then ask those who are willing to share their experiences.	Discussion, experience sharing	Markers, newsprints	45 minutes	
2	Sharing the findings of research on service user/caregiver involvement in Nepal	• Share the research findings of service user and caregiver involvement study through powerpoint presentation. • Ask participants to discuss and comment on research findings.	Discussion, presentations	Multimedia,	20 minutes	
3	Sustainable model of involvement	• Divide the participants into 3-4 groups • Provide a case study of service user /caregiver facing problems	Case study, group work, discussion,	Newsprint, markers, case study, multimedia	50 Minutes	

		in community and during treatments • Ask the groups to discuss how people with mental health /caregivers individually or as group can help overcome such problems. • Ask the groups to also discuss about sustainable models of involving service user/care giver in policy programme and research. • Ask each group to present their discussion • Ask one of the people with mental health problem representatives to share his/her experience of involvement and how s/he was able to overcome the challenges to become a people with mental health problem advocate. • Summarize and discuss major points from the group work.	presentation			
4	Summary and conclusion	• Summarize the main points of the session and conclude the session			5 Minutes	

Lesson Plan: Session 8

Stigma and Discrimination

Total time: 1 hour 45 minutes

Objectives: The participants will be able to;

- Describe the meaning of stigma and discrimination
- Analyse the consequences of stigma and discrimination
- Suggest how stigma and discrimination can be reduced

SN	Topic	Activities	Methods	Materials & Resources	Duration	Facilitator
1	Introduction to stigma and discrimination	• Play a game called " Khola tarne tara birami natarne Khel"- Ask the participants to volunteer to become parents, teachers, students, government officers and patients. You as an in-charge of river crossing allow all others to cross the river but not the patients. Ask the rest of the participants to observe your behaviour. (See Box No. 2 for Illustrations) • Ask all participants what they understand by stigma and discrimination relating to the recently played game. • Ask participants what names are used in Nepal for persons with mental illness	Brainstorming, discussion, presentation	Multimedia, board/newsprint, marker	15 minutes	

		• Briefly describe the meaning of stigma and discrimination, and discuss internalized/externalized stigma (through power point presentation)				
2	Experiences of stigma and discrimination	• Divide the participants in pairs or groups and ask them to discuss their experiences of stigma and discrimination- either direct, or those experienced by family members or others in the community. Ask them to discuss where such stigma took place and what was its impact. (15 minutes) • 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 and discrimination take place in various places such as: family, school, workplace, health centres, community, and government • Ask participants what they thought were impact of stigma and discrimination. List them on the board/newsprint and	Group/ pair sharing, discussion	Multimedia, newsprint, marker	30 minutes	

		discuss.				
3	Ways to reduce stigma Share findings from the feasibility study of anti-stigma intervention called buddy intervention	• Divide the participants into 3 groups. • Ask each group to draw a social mapping of possible stigmatizing people and places and discuss different ways of reducing stigma- what needs to be done in - Individual level (group 1) - Community level (group 2) - National level (group 3) • Ask the groups to present them to other participants • Facilitator can give examples of various research findings on how to reduce stigma and initiations taken in different countries. •	Group work, presentation	Multimedia, board/newsprint, marker	55 minutes	
4	Summary and conclusion	• Summarize the main points of the session and conclude the session			5 Minutes	

Box Number 2: Illustrations for the game " Khola tarne tara birami natarne Khel"

Illustrations

1. Ask 6 volunteers to come out of the training/workshop room and give them the following instructions:The participants in the training room should not listen these instructions.

2. Divide the 6 volunteers into two groups

3. Ask them to nominate one person from each group to act as sick person (birami)

4. Tell them that there will be two river banks (two flip charts placed in between the river) and while crossing the river the sick person will be asking you for help, at that time you don't help saying that if you help the sick person you will have a bad luck and you might drawn. You give hands to another normal person instead and help him/her out to cross the river. At the end all the normal people would have crossed the river and only sick persons would be left out, who will be still crying out for help and finally they would get upset and isolated

5. In the training/workshop room place a big flip chart in two places (indicating the banks of the river).

6. Instruct the participants in the training room to carefully observe the role play to be performed and note the stigmatizing events in the role play.

7. Ask the volunteers to come inside and perform the role play as explained earlier.

8. Allow the role play to continue for about 3-4 minutes, not longer.

9. Then ask the experiences of the volunteers who performed the role of a sick person adding on what volunteer said explain further the topics related to stigma.

10. Then ask the experiences of people who were stigmatizing the sick persons. Explain how this happens in the community.

Reading Material: Session 8

Stigma and Discrimination

8.1. Introduction to Stigma and Discrimination

Stigma is an inner feeling of disliking which is expressed in various ways like, fear of getting infected, avoidance, discrimination in behaviour, hate, humiliating and dishonouring. Discrimination is visible expression of stigma, superior feeling and rejection of the individual.
Reduction of stigma and discrimination has posed a serious challenge for activists and implementers alike. The implications of stigma and discrimination have multiple effects. It ranges from denial of services and support to not accessing the service for the fear of being stigmatized and denied.

Stigma and discrimination associated with certain illnesses have remained a global public health concern over the years. Stigma has been linked with problems relating to knowledge (ignorance) and attitudes (prejudice) while discrimination has largely been related to behaviour. Different types of stigma exist ranging from public (externalized or experienced stigma) to self-stigma (internalized stigma) (37, 38).
Stigma associated with mental illness is widespread. It affects different life domains e.g. interpersonal relationships, housing, employment and recovery from mental illness causing social exclusion and isolation for those afflicted (39).

Stigma is considered to be an opinion or judgment held by individuals or society. If these prepositions are acted upon, these actions may be considered to be discriminatory. Stigma is the negative stereotype and discrimination is the behaviour that results from this negative stereotype.

People with mental health problems experience prejudice and discrimination in almost every aspect of their lives. Many have said the stigma of mental ill health is more disabling than the

illness itself. Research has shown that people with mental health problems are pre-judged, find it hard to get jobs and sustain friendships and relationships. Research has also shown that ignorance, fear, and stereotypes presented in the newspapers, on the TV and at the cinema, all contribute to negative attitudes towards mental ill health. Most people have little knowledge about mental illness and their opinions are often factually incorrect.

8.2. Consequences of Stigma and Discrimination

- Limiting access to housing and employment
- Damaging social relationships and social participation
- Reducing self-esteem and dignity
- Lack of control and influence in how services are designed and delivered
- Abuse of human rights
- Loss of income/livelihood
- Loss of hope and feelings of worthlessness
- Loss of reputation
- Withdrawal of care giving in the home
- Develop an intense fear of "coming out"
- Delay seeking necessary mental health care
- Develop a practice of self-stigmatization

8.3. Reduction of Stigma and Discrimination against People with Mental Health Problems(40)

Knowing the facts.

There is a need to educate people about mental health problems and sensitize them about the facts of mental health problems and clear their misconception about mental illness.

Aware of attitudes and behaviour

We can change our judgemental thinking by being aware about our own attitudes and behaviour. We must see the person beyond their mental illness; they have many other personal attributes that do not disappear just because they also have a mental illness.

Choosing words carefully

The way we speak can affect the way other people think and speak. We must not use hurtful language.

Educating others

We have to find opportunities to pass on facts and positive attitudes about people with mental health problems. If our friends, family, co-workers or even the media present information that is not true, we need to challenge their myths and stereotypes.

Focus on the positive

People with mental health and substance use problems can contribute to the society.. Their health problems are just one part of who they are. We have to recognize and applaud the positive aspects of people with mental health problems.

Support people

If any family members, friends or co-workers with substance use or mental health problems, support their choices and encourage their efforts to get well.

Include everyone

While providing the services, we should include everyone irrespective of their caste, creed, religion, language and socio-economic status. People with mental illness should also get the opportunity as per their level like access to things such as jobs, health care and education. Moreover, emphasis must be given to make the services more user friendly so that people of all kinds have access to it.

Others measure to reduce stigma and discrimination

- Community education on mental disorders (prevalence, causes, symptoms, treatment, myths and prejudices)
- Development of demonstration areas with community care and social integration for persons with mental disorders
- Anti-stigma training for teachers and health workers
- Education of persons working in the mass media, aimed at changing stereotypes and misconceptions about mental disorders
- Psycho education for consumers and families on how to live with persons who have mental disorders
- Empowerment of consumer and family organizations
- Improvement of mental health services (quality, access, deinstitutionalization, community care)
- Legislation on the rights of persons with mental disorders

Lesson Plan: Session 9

Group Activity: Developing a Plan of Action (on whatPeople with mental health problemspeople with mental health problems and care givers can do practically in their community for their involvement in strengthening health systems)

Total time: 1 hour

Objective: The participants will be able to;

- List ways on what they as People with mental health problems and caregivers can do practically in their community from what they have learned in previous sessions

SN	Topic	Activities	Methods	Materials & Resources	Duration	Facilitator
1	Group activity	• Divide the participants into 2-3 groups. • 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 the day-mainly related to service user/caregiver involvement in Nepal and stigma reduction. • Ask them to come up with activity plan and present them in the group in creative ways (give some ideas if needed such as dramas, songs etc.)	Group work	Newsprints, markers	45 Minutes	

2	Seeking commitment	• Ask the participants to declare the activities that they will be doing to use and transfer the knowledge they have gained through the training and ask them to sign the declaration.			10 Minutes	
3	Summary and conclusion	• Summarize the main points of the session and conclude the session			5 Minutes	

Lesson Plan: Session 10

Ending/Closing Session

Total time: 15 minutes

Objectives:

- To conduct post-test evaluation
- To wrap-up the capacity building training

SN	Topic	Activities	Methods	Materials & Resources	Duration	Facilitator
1	Ending	• Summarize and conclude the two-days training • Conduct post-test evaluation(See Annex II)	Group discussion, evaluation	Newsprint, marker, post-test evaluation form	15 minutes	

References

1. Herrman H, Saxena S, Moodie R. Promoting mental health: concepts, emerging evidence, practice: a report of the World Health Organization, Department of Mental Health and Substance Abuse in collaboration with the Victorian Health Promotion Foundation and the University of Melbourne: World Health Organization; 2005.
2. An introduction to mental health Facilitator's Manual for Training Community Health Workers in India [Internet]. 2009 [cited 1st January 2017]. Available from: http://basicneeds.org/download/PUB%20-%20An%20Introduction%20to%20Mental%20Health%20-%20Facilitator%E2%80%99s%20Manual%20for%20Training%20Community%20Health%20Workers%20in%20India.pdf.
3. Kinderman P. A psychological model of mental disorder. Harvard review of psychiatry. 2005;13(4):206-17.
4. Fernald D. Psychology: six perspectives: Sage Publications; 2007.
5. Committee I-AS. IASC guidelines on mental health and psychosocial support in emergency settings: Inter-Agency Standing Committee; 2007.
6. Martikainen P, Bartley M, Lahelma E. Psychosocial determinants of health in social epidemiology. International Journal of Epidemiology. 2002;31(6):1091-3.
7. Sorsdahl K, Stein DJ, Flisher AJ. Traditional healer attitudes and beliefs regarding referral of the mentally ill to Western doctors in South Africa. Transcultural Psychiatry. 2010;47(4):591-609.
8. Whiteford HA, Degenhardt L, Rehm J, Baxter AJ, Ferrari AJ, Erskine HE, et al. Global Burden of disease attributable to mental and substance use disorders: findings from the Global Burden of Disease Study 2010. The Lancet. 2013;382(9904):1575-86.
9. Whiteford HA, Ferrari AJ, Degenhardt L, Feigin V, Vos T. The global burden of mental, neurological and substance use disorders: an analysis from the global burden of disease study 2010. PLoS One. 2015;10(2):e0116820.
10. v. Stricklin ML. Community-based care: Back to the future! Disability and Rehabilitation. 1997;19(4):158-62.
11. Organization WH. Task shifting: rational redistribution of tasks among health workforce teams: global recommendations and guidelines. 2007.
12. Organization WH. Increasing access to health workers in remote and rural areas through improved retention: global policy recommendations: World Health Organization; 2010.
13. Saria S. Suicides among Women-A Sad Reality in Nepal. Health for All. 2015;2(1):9-10.
14. Luitel NP, Jordans MJ, Sapkota RP, Tol WA, Kohrt BA, Thapa SB, et al. Conflict and mental health: a cross-sectional epidemiological study in Nepal. Social psychiatry and psychiatric epidemiology. 2013;48(2):183-93.
15. World Health Organization. Mental health atlas: country profile 2014 [27/08/2016]. Available from: http://www.who.int/mental_health/evidence/atlas/profiles/npl_mh_profile.pdf?ua=1.

16. WHO. WHO-AIMS report on mental health system in Nepal. Kathmandu, Nepal: WHO and Ministry of Health, 2006.
17. Luitel NP, Jordans MJ, Adhikari A, Upadhaya N, Hanlon C, Lund C, et al. Mental health care in Nepal: current situation and challenges for development of a district mental health care plan. Conflict and health. 2015;9(1):1.
18. UN General Assembly. Universal declaration of human rights. UN General Assembly. 1948.
19. Freeman M, Pathare S. WHO resource book on mental health, human rights and legislation: World Health Organization; 2005.
20. Convention on the Rights of Persons with Disabilities [Internet]. 2006 [cited 25 June 2015]. Available from: http://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf.
21. Government of Nepal. Muluki Ain. 1964.
22. Ministry of Health. National Health Policy, 1991. In: Services DoH, editor. Kathmandu1991.
23. Ministry of Health. National Mental Health Policy, 1996. Kathmandu1997.
24. Ministry of Health and Population. Nepal Health Sector Support Program_II (2010-2015). Kathmandu2010.
25. Government of Nepal. Multisectoral action plan for prevention and control of non-communicable diseases in Nepal 2014-2020. Kathmandu: 2014.
26. Ministry of Law and Justice. Local Self Governance Act, 2055. Kathmandu1999.
27. Social Welfare Act, 2049, (1992).
28. National Health Policy, (2014).
29. Chamberlin J. On our own: Patient-controlled alternatives to the mental health system: McGraw-Hill; 1978.
30. Chamberlin J. User/consumer involvement in mental health service delivery. Epidemiologia e Psichiatria Sociale. 2005;14(01):10-4.
31. UNICEF, World Health Organization. Primary health care: report of the International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978. 1978.
32. Reaume G. Lunatic to patient to person: nomenclature in psychiatric history and the influence of patients' activism in North America. International Journal of Law and Psychiatry. 2002;25(4):405-26.
33. Arnstein SR. A ladder of citizen participation. Journal of the American Institute of planners. 1969;35(4):216-24.
34. Substance Misuse RCT. Service user involvement framework27/09/2016. Available from: http://www.substancemisuserct.co.uk/staff/adults/frameworks/user%20involvement.pdf.
35. TwoCan Associates. [22/09/2016]. Available from: http://www.twocanassociates.co.uk/routemap/.
36. 37. Corrigan PW, Watson AC. Understanding the impact of stigma on people with mental illness. World Psychiatry. 2002;1(1):16.
38. Corrigan PW, Kerr A, Knudsen L. The stigma of mental illness: Explanatory models and methods for change. Applied and Preventive Psychology. 2005;11(3):179-90.
39. Link BG, Phelan JC. Conceptualizing stigma. Annual review of Sociology. 2001:363-85.

40. Canadian Mental Health Association. Seven Important Things We Can Do to Reduce Stigma and Discrimination 2014 [cited 2016 30 December]. Available from: http://www.mendthemind.ca/stigma/seven-important-things-we-can-do-reduce-stigma-and-discrimination.

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AnnexI

Evaluation of workshop for service user and caregiver involvement (pre- and post structured questions)

Please **circle** the rating that fits you best:

	Strongly disagree	Disagree	Don't know	Agree	Strongly agree
1) I understand about types of mental illness	1	2	0	3	4
2) I understand about the treatments that can help people with mental illness	1	2	0	3	4
3) I understand about the international protections (and protections within my country) for the rights of people with mental health problems	1	2	0	3	4
4) I understand what kinds of contributions *patients* [*appropriate term] and their families can make to improving mental health care in my district (local area)	1	2	0	3	4
5) I understand how I can contribute to improving mental health care in my district (local area)	1	2	0	3	4
6) I understand how I can contribute to the development of national mental health policies and laws in [my country]	1	2	0	3	4
7) I understand about the experiences of other people with mental health problems in our district	1	2	0	3	4

Annex II

Evaluation of workshop for service user and caregiver involvement (post only, open-ended questions)

1. What did you find useful about the workshop?

2. What new things did you learn during the workshop?

3. What could have been improved?

4. Any other comments?