Transforming the TB Response - Capacity Building of Communities to be Change Agents

Training Manual 2019

Global Coalition
of TB Activists

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FOREWORD BY PHUMEZA TISILE

XDR-TB Survivor and Advocate,

TB Proof

I congratulate the Global Coalition of TB Activists for developing the Transforming the TB Response – Capacity Building of Communities to be Change-Agents Training Manual. TB continues to be one of the leading killers in the world and yet the voices of the affected communities are pushed to the side lines from the global TB response. This is largely true because there continues to be a dearth of comprehensive tools for community empowerment that can turn communities into advocates and informed stakeholders, demanding better access to care and treatment. With this manual, GCTA is truly taking a large leap to fill the gap and build a stronger multi-faceted TB response.

I personally felt the brunt of not having a community that completely understood the effects that the TB treatment can have on a person. When my XDR TB treatment left me deaf for 5 years, its silence made me realise that the voices of the TB affected communities are not being heard. Our lived experiences are not accounted for. Globally, many are still subjected to toxic injectables that cause unfathomable pain and discomfort and often leave many disabled for life. For every Phumeza, there are thousands more who never get the chance to voice their concern and are left to the voices of the world, in order to survive. This should not be a choice that anyone has to take. To truly eliminate TB we need to put that voice at the centre. We need a community that understands TB and can advocate for more tools like this manual to gear affected communities to become advocates and activists and demand safer and shorter regimes.

Affected communities are not just numbers, we are breathing-living people who come with a pool of knowledge and lived experience. Support communities and I know that together we can change the tide at every bend and truly envision a future without TB.

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GLOSSARY

ADR : adverse drug reaction

ART : anti-retroviral therapy

BCG : Bacillus Calmette-Guérin

CBNAAT : cartridge based nucleic acid amplification test

CRG-SI : Global Fund Community Rights and Gender Strategic Initiative

CSO : civil society organization

DR-TB : drug resistant TB

DST : drug susceptibility testing

DS-TB : drug-sensitive tuberculosis

EMA : European Medicines Agency

EP TB : extrapulmonary tuberculosis

FDA : Food and Drug Administration

FDC : fixed dose combination

GCTA : The Global Coalition of TB Activists

HBC : high burden countries

HIV : human Immunodeficiency virus

IGRA : interferon gamma release assays

INH : isoniazid

IPT : isoniazid preventive therapy

LBC : low burden countries

LPA : line Probe Assay

LTBI : latent TB Infection

MDR-TB : multi drug-resistant tuberculosis

MGIT   : mycobacteria growth indicator tube

MRI   : magnetic resonance imaging

MTB   : mycobacterium tuberculosis

NGO   : nongovernmental organization

NTP   : National Tuberculosis Program

PLHIV   : people living with HIV

RR-TB   : rifampicin-resistant TB

TNF   : tumour necrosis factor

TST   : tuberculin skin test

TB   : tuberculosis

UN   : United Nations

UV   : ultra violet

WHO   : World Health Organization

XDR-TB   : extensively drug resistant TB

ACKNOWLEDGEMENTS

THERE IS NO GREATER POWER FOR CHANGE GREATER THAN A COMMUNITY DISCOVERING WHAT IT CARES ABOUT.

-MARGARET J WHEATLEY

BACKGROUND

More than 10 million people become ill with tuberculosis (TB) each year, and of this more than 3 million are not diagnosed, treated, or officially registered by national TB programmes. Collectively, these "missed" millions are a global public health failure. This is especially the case considering that TB is airborne and that each undiagnosed and untreated person can infect as many as 15 individuals per year.

The Global Plan to End TB: The Paradigm shift: 2016-2020 states that people with TB and the groups that represent them must be at the heart of the paradigm shift. Affected communities (people who have been directly affected by TB; this could include someone living with TB as well as his/her family or someone being treated for TB) must be included in every area of decision-making, serving on boards of organizations and institutions that provide care, and sharing their experience and knowledge as equal and valuable partners in all TB forums. The community must also be resourced and empowered to form caucuses, to choose its own representatives, and to interact with the media. People with TB and their communities must be partners in the design and planning of strategies to end TB, and given a key role in monitoring and evaluation, especially at the point of need. New tools, including social media, social auditing and social observatories, have the potential to be used alongside traditional tools to make progress in this area.

The Global Coalition of TB Activists (GCTA) is a coalition of representatives from and of the TB affected communities. GCTA aims to bring together activists from diverse backgrounds and regions to ensure that TB affected communities are at the center of all processes on TB. GCTA aims to be an advocacy platform and effectively represent TB affected communities in order to influence global TB control agenda through patient empowerment, strategic advocacy and community mobilization.

Under the project supported by Global Fund Community Rights and Gender Strategic Initiative (CRG-SI) GCTA aims to develop adaptable TB treatment literacy and advocacy materials and build capacity of community members as Change Agents or advocates to support National TB Programs (NTPs) in finding missing people with TB and further ensure early detection, diagnosis and treatment initiation.

PURPOSE OF THE TRAINING

The overall purpose of the Change Agent Training is to bring together affected community members from inadequately served populations to discuss issues at the global, regional and country level that are relevant to enable community-led TB response. The training will also provide a valuable opportunity to the community members to build their advocacy skills for future response to better health care. The community members will use this platform to enhance their knowledge on latest development on TB treatment regime, and access issues, gaps and challenges.

GOAL

To establish a group of effective Change Agents to advocate and support NTPs in finding the missing people with TB, ensuring early detection, diagnosis and treatment initiation.

TRAINING PARTICIPANTS

It is envisaged that this manual will be used for the training of community members from inadequately served populations.

Participants will be identified by local partner agencies, preferably community members who can incorporate TB-related issues into their day-to-day work. Participants will be TB survivors and people affected by TB and inadequately served populations for TB (people who are vulnerable, inadequately served or at-risk of TB infection and illness: such as people living with HIV, people who use drugs, people who have increased exposure to TB due to where they live or work, people who have limited access to quality TB services, and people at increased risk of TB because of biological or behavioral factors that compromise immune function).

TRAINING OBJECTIVES

- To bring together community members including TB survivors, NGO staff, members from the key population most vulnerable to TB and TB champions to discuss TB issues at the global, regional and country level

- To provide training to community members on TB and advocacy

- To enhance community members' knowledge on latest developments on TB treatment regime, availability, gaps and challenges.

Training Content

The training will address three major themes under the following sections:

1. TB basics

2. Advocacy

3. Communication

ABOUT THIS GUIDE

This module has been designed for a three-day training. Each session follows the structure given below:

- Duration: Approximate amount of time required for the session.

- Training Aids/Materials Required: A suggested list of materials required during the training including audio-visual equipment (such as LCD projector, laptop, sound system, white screen for power-point presentation), white board, board markers, permanent markers in different colours, post-it notes of different colors, flip charts, other training material handouts, reference materials, masking tape, scissors, white paper A4 size, and feedback forms.

- Learning Objective(s): Describes the desired learning objective to be achieved by participants by the end of the session.

- Methodology: Describes step-by-step participatory methods that will be employed to engage participants in the learning process.

- Facilitators' Note: Notes to provide the facilitator with useful information on the topic or tips for facilitating an activity.

- Additional Resources: Information to supplement specific topics discussed in the sessions. Facilitators are required to read this section prior to commencement of the training sessions.

- Pre and Post Training Assessment: Participants are required to complete a pre-training self-assessment questionnaire at the beginning. A post-training questionnaire will also need to be completed when all the sessions have been delivered. These will be analysed to assess the progress of the participants through the process of participatory learning.

- Feedback Forms: Participants will be given a very brief and simple feedback form to complete at the end of each day's sessions. This feedback will help the team of facilitators and organizers to respond to their concerns, as well as to help plan subsequent sessions appropriately.

Overall Guidelines for Facilitator(s):

Flexibility: Facilitators may choose to adapt the sequences, timings and methodology as per the requirements of the participants.

Adult Learning Principles: The team of facilitators should employ participatory methods to ensure optimal engagement of participants in the learning process and encourage equal participation, learning and experience sharing.

Confidentiality: Facilitators should maintain confidentiality particularly with regard to any personal issues discussed throughout the duration of the training; and ensure that no audio or video recordings are taken without the consent of the participants.

Objectivity: The role of the facilitators is to facilitate discussion and encourage participation during group activities, but care must be taken to ensure that personal views or opinions are not imposed on the participants.

DAY 1

SESSION 1
SETTING THE TONE

DAY 1
SESSION 1: SETTING THE TONE

Duration: 50 minutes

Training Aids/Materials Required:

- Flipchart

- Coloured markers

- Cards/post-it notes

- PowerPoint presentation

- Laptop

- LCD projector

- Pre-training self-assessment forms

- Slips of paper

METHODOLOGY

Step 1.1: Introductions (10 minutes)

Conduct an icebreaker exercise to help the participants to get to know each other better over the course of the three-day training.

Suggested exercise: 'Know your Partner'

Prepare slips of paper in advance with names of animals written on them, with each name constituting a pair. (The number will depend on the number of participants.) Hand out the folded slips of paper to all participants and ask them to find their partners without any verbal communication. Once they form pairs, ask them to gather information about each other (names, organization, hobbies, skills and so on) and use this information to introduce each other to the larger group.

Step 1.2: Expectation from the Training (10 minutes)

Provide cards/post-its of various colors to each participant and ask them to note down their expectations from the training. Put these up on the board and read aloud the main expectations. At the end of the training the expectations may be revisited to understand if the expectations of the participants have been met.

Step 1.3: Training Overview and Objectives (5 minutes)

With the aid of PowerPoint slides, highlight the objectives and overview of the training. Referring to the expectations from the previous session, inform participant about the ones that will be addressed during the course of the training. Also inform participants that if some of the expectations may be outside the scope of the training, they may be addressed by the team of facilitators through informal discussions.

Step 1.4: Ground Rules (5 minutes)

Interact with participants to list down ground rules to be followed during the training so that there is maximum learning and sharing among all without any distractions in the room/hall. Note their suggestions on a flip chart and put it up on one side of the hall. These ground-rules may be referred to in subsequent sessions especially in the case of new participants or facilitators.

Step 1.5: Assigning Participants for Recap Next Day (5 minutes)

Request volunteers from among the participants to reflect on key points from each day's sessions at the start of the following day's sessions.

Step 1.6: Pre-Training Self-Assessment (15 minutes)

Request participants to complete a pre-training self-assessment questionnaire, and inform them that a similar post-training assessment will also be administered after the last session in this training. The facilitator should explain that this simple assessment is not a test, but an exercise that will be helpful in assessing the progressive learning of the participants and also aid in measuring the effectiveness of the sessions delivered.

SESSION 2

TB AT A GLANCE

SESSION 2: TB AT A GLANCE

Duration: 4 hours

Training Aids/Materials Required:

- Flipchart

- Sheets of chart paper

- Coloured markers

- PowerPoint presentation

- Laptop

- LCD projector

- Rewards/gifts for participants in the exercise

- Handout-A

Learning Objectives: By the end of this session participants will be able to describe the modes of TB transmission, its diagnosis and treatment; identify barriers to access in the pathway to cure; and prioritize barriers requiring advocacy initiatives

METHODOLOGY

Step 2.1: 'Who Wants to Be A Millionaire?' – An Interactive Exercise

Prepare 8 to 10 questions on simple facts about tuberculosis in advance. Ask participants to provide answers to these questions. The participant with the most number of correct answers receives a reward.

Step 2.2: Basics of TB and Global and Country Data on TB

Discuss the basics of tuberculosis on the topics below:

1. Definition of TB

2. Pulmonary TB and Extra Pulmonary TB

3. Dormant TB

4. Difference between latent TB and TB disease

5. Symptoms of TB

6. How is TB treated?

7. TB treatment regime

8. Treatment course of DR TB and XDR TB

9. Common Adverse Events (AEs) and how doctors should respond

10. Challenges of DR TB and XDR TB treatment

11. Barrier to access TB treatment

12. TB Facts

13. Global data on TB (WHO report 2018)

14. Country data on TB (NTP report 2018)

Facilitators' Note:

Please distribute handout.

[As an alternative option, use culture/context appropriate audio-visual aids and supplement the messages with the handouts provided at the end of this section.]

Step 2.3: Discussion

Open the floor for questions and provide appropriate answers and clarifications

Step 2.4: Pathway to Cure - Mapping Barriers

Preparatory Work for the Facilitator:

- Paste 7 sheets of chart paper side-by-side on the walls for each of the following areas:

    1. Developing Symptoms

    2. Seeking Care

    3. Getting a Diagnosis

    4. Starting Treatment

    5. Completing Treatment

    6. Getting Cured

    7. Getting Back on Track

- Draw a horizontal line along the middle of each chart paper, dividing them into two sections each. The upper sections represent the barriers faced at the health system level (public or private), while the lower sections represent barriers at the individual, family or community level.

Facilitators' Note:

Participants may need to be informed that a long lead time at a particular point of care should also be considered a barrier even if this is considered 'normal' or 'usual' by people delivering the care.

- Divide participants into groups and assign each group a topic from the topics listed above. Ask them to discuss the kind of barriers faced along the pathway to cure and to identify specific points. Each point is noted on separate post-it notes.

- Identify Barriers: Ask group members to gather around the chart papers pasted on the walls and ask each group to decide where

each of the points should be placed on the appropriate sections of the chart paper. Participants could also identify commonality in barriers and which of them are more frequent across the group.

- Summarize: According to the points provided by the participants, list down the barriers, prioritize them, and share with the participants.

Facilitators' Note:

Please ensure that the sheets of chart paper pasted on the wall are retained for reference during the sessions on advocacy on Day 2 of the training.

HANDOUT - A

What is TB? How Does It Spread?

- TB is an infectious disease caused by a bacteria called 'Mycobacterium Tuberculosis'.

- TB mostly affects the lungs (causing pulmonary TB) but can also affect other organs, including bones and joints, kidneys, brain, genitals, urinary tract, spine, lymphatic system, intestines, etc. TB can infect any part of the body except the hair and nails.

- When TB affects any organ other than the lungs, it is called extra-pulmonary TB.

- TB spreads through air. When someone with pulmonary TB coughs, spits or sneezes, droplets of mucous carrying TB germs may be expelled into the air. Anyone who inhales these droplets could develop an active TB infection.

- TB can affect people belonging to any age group or economic strata.

- Since TB is an airborne disease, anyone who inhales the bacteria can get infected with TB.

- When someone inhales the TB bacteria, it could settle in the lungs and cause pulmonary TB. However, it could also spread to other organs via the blood stream and lymph system and cause an infection in whichever part of the body it settles in.

- Many of us have already inhaled the TB bacteria and carry it within our bodies, often without our knowledge. All of us who inhale the TB bacteria do not become ill with the disease. In most people, the normal immune system of the body is able to keep the bacteria well under control. In about 10% of the people who harbour the bacteria, the germs multiply and cause TB disease.

- A person with TB infection usually develops TB disease when his or her immunity is lowered.

- Poor nutrition, diabetes and HIV are some of the risk factors for TB, as they all lower a person's immunity.

- Smoking is also a risk factor as it weakens the lungs.

- Anyone in close contact with someone who has pulmonary TB is also at a greater risk of developing TB.

DIAGNOSING TB

- The symptoms of pulmonary or lung TB may include:

  ◊ Persistent cough

  ◊ Cough of any duration in people who are living with HIV

  ◊ Blood in the phlegm (haemoptysis)

  ◊ Fever and night sweats

  ◊ Chest pain

  ◊ Loss of appetite

  ◊ Loss of weight

  ◊ Breathlessness

In children, specific symptoms such as falling off the growth curve, reduced playfulness.

- If someone has had a persistent cough, it's important to consult a doctor and get tested for TB.

- It is important to note that someone has latent TB if they are infected with the TB bacteria but do not have signs of active TB disease and do not feel ill. However, they can develop active TB disease in the future.

- Pulmonary TB is diagnosed by testing the sputum sample by microscope, any rapid molecular tests such as cartridge based nucleic acid amplification test (CBNAAT) or by sputum culture.

- In the case of extra-pulmonary TB, the person will develop symptoms that are specific to the affected area. For example, in a case of intestinal TB, the person may experience diarrhoea or in the case of TB of a particular joint, the patient may experience pain and

swelling of that area. Besides this, fever, loss of appetite and weight loss is also possible.

- Extra-pulmonary TB is ideally diagnosed by examining the affected organ or site, eg. Lymph node. This is done by a biopsy, in which a small bit of the tissue or fluid from the affected part is removed through a surgical procedure and examined under the microscope. Alternatively, the sample can be tested by CBNAAT. When a biopsy is not feasible, for instance in the case of the spine, the diagnosis is made with a combination of X-rays, CT or MRI scans and symptoms. A genotypic test would be the preferred test over microscopy especially in PLHIV and children.

- Serological tests (blood tests) are very often inaccurate and have been banned by WHO for the diagnosis of TB. In other words, a blood test will not tell someone if they have latent TB infection or TB disease.

- The Mantoux test is a skin test. It checks to see if the immune system of the body recognizes TB, which is a sign that someone may have TB in the system. However, the Mantoux test cannot be used to determine active TB disease but only the presence of the bacteria in the system. A Mantoux test cannot definitively tell if someone has TB disease or not, particularly in the case of adults. However, in children, the Mantoux test is often used to diagnose TB disease.

- Screening is sometimes done prior to referring an individual for diagnosis. Screening means assessing whether someone is vulnerable to the disease and needs to be referred for diagnosis. Symptom screening, for example, means assessing whether a person has any of the TB symptoms and is often used as a tool for finding missed people with TB.

TREATING TB

- TB is a curable disease.

- The course of the TB treatment is 6 months.

- For drug resistant form of TB (DR TB), the duration of treatment is much longer, often up to two years.

- TB is treated with a combination of drugs (HREZ-Isoniazid, Rifampicin, Ethambutol and Pyrazinamide). These drugs are given daily and sometimes as fixed dosed combinations (FDC).

- Most national TB guidelines assign a treatment supporter to every person diagnosed with TB, who will be responsible for ensuring that medicines are taken as required, updating the treatment cards, reminders to go for reviews on time, follow-up if there are any side effects and ensuring that the entire course of treatment is completed.

- It is very important to complete the full course of treatment. It is likely that someone with TB will feel better in a few weeks after starting treatment but that does not mean s/he is cured. Anti-TB medicines are strong antibiotics and it is essential to complete the course of medicines to ensure that one does not have a recurrence of TB and that the body does not become resistant to the anti-TB drugs (and cause a more serious complication, i.e drug-resistant TB).

- TB can easily be treated on an outpatient basis. Only severe cases and complicated TB treatment require hospitalisation.

- Most countries offer free TB treatment at government centres. However, costs in the private sector vary tremendously.

- For most people TB treatment is safe and does not cause side effects. However, some people may develop side effects and they should be evaluated by the doctor and offered testing to see if one of the TB medicines is the cause of the problem.

- Some side effects of the TB treatment include vomiting, nausea, problems with the liver, and problems with the nerves in the hands or feet. Early identification of these side effects is important to make sure they do not cause permanent damage. People on TB treatment experiencing side effects should talk to their doctors right away.

			Possible Adverse Drug Reactions (ADR) that need monitoring		

Sl. No.	Adverse Drug Reaction	Early Signs and Symptoms	Usual Offending Agents
1	Gastro Intestinal Symptoms	Nausea Vomiting Gastritis Diarhoea	Most drugs, especially Ethionamide / PAS / Pyrazinamide / Ethambutol
2	Balance	Giddiness Oversleeping Poor concentration	Amino glycosides Ethionamide Quinolones and / or Pyrazinamide
3	Vision	Blurring of vision Disturbance in color vision	Ethambutol
4	Kidney function	Less than normal urination Total stoppage of urination Puffiness of face Swelling of feet	Kanamycin
5	Movement	Joint pains	Pyrazinamide Quinolones

Note: Any adverse reaction must be reported to the attending physician, in order to assess the continuity of the medication either by reducing the dose or by stopping the medication.

6	Skin reactions	Itching Localised Rash Generalized erythematous rash associated with fever and/or mucous membrane involvement	Any of the drugs may give rise to this
7	Liver	Loss of appetite Nausea/Vomiting Abdominal discomfort Dark colored urine Jaundice	Ethionamide Pyrazinamide
8	Neural	Pain and/or tingling sensations in any part of the body especially feet and hands	Cycloserine Ethionamide Linezolid
9	Neural	Convulsions Fits	Quinolones Cycloserine
10	Mental Health	Depressions Excessive chatting Unusual violent tendencies Suicidal tendencies	Cycloserine Quinolones Ethionamide

11	Hearing and ear related	Ringing in the ear Deafness Unsteady gait Patient has a tendency to lose balance and fall	Aminoglycoside
12	Thyroid Function	Lethargy/ Tiredness Slowing of activities Puffiness of face Swelling of the thyroid (neck swelling)	PAS Ethionamide
13	Gastrointestinal	Diarrhoea, nausea, or vomiting.	Imipenem
14	Skin	Orange/red discoloration of skin, conjunctiva, cornea and body fluids. Dry skin, pruritus, rash, ichthyosis, xerosis. Gastrointestinal intolerance. Photosensitivity.	Clofazimine
15	Joints, Heart	Chest discomfort, palpitation, Joint pains, specifically small joints like toes	Bedaquiline and Delamanid

DRUG-RESISTANT TB

- Drug resistance means that the TB medicines are not able to kill the TB bacteria in a person. The bacteria have become resistant to some specific drugs, which are therefore no longer effective.

- When someone with TB develops resistance to two of the most important drugs used in the treatment (Isoniazid and Rifampicin), with/without resistance to other drugs, the person is said to have MDR-TB.

- Drug-resistant forms of TB spread through the air just like other forms of TB.

- In some cases, people directly get MDR-TB by inhaling MDR-TB infected droplets.

- The symptoms of MDR-TB are the same as 'ordinary' TB – a persistent cough, chest pain, fever, loss of appetite and weight.

- Those who come into frequent contact with someone who already has MDR-TB or a TB patient whose treatment has been interrupted, are at a higher risk of developing MDR-TB.

- MDR TB is diagnosed by CBNAAT, LPA, MGIT and conventional culture methods. However, it takes anywhere from three to twelve weeks to get results from culture tests

- In 2012 and 2014, two new drugs: Bedaquiline[1] and Delamanid[2], were conditionally approved by the FDA (Food and Drug Administration) and EMA (European Medicines Agency) for treating MDR-TB; and WHO has issued guidelines for their usage.

- XDR-TB is an advanced stage of MDR-TB in which, the bacteria, in addition to being resistant to isoniazid and rifampicin are also resistant to two of the most potent drugs used to treat MDR-TB, i.e, flouroquinolones and the injectables. Since someone with XDR-TB is resistant to most of the core drugs used to treat TB, treatment options are limited, highly expensive and have many side effects.

- Everyone has a right to the best possible treatment free of charge and people also have a right to know about the side effects before starting on treatment (people-centred, rights-based TB response).

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1   http://www.who.int/tb/challenges/mdr/bedaquiline/en/
2   http://www.who.int/tb/publications/delamanid-in-mdr-tb-treatment/en/

TB AND CO-INFECTIONS

- People living with HIV are up to 20 to 30 times more likely to fall ill with TB than people without HIV. TB is the most common opportunistic infection for people living with HIV. This means that those with HIV are at increased risk of TB and considered vulnerable to TB on account of their lowered immunity.

- HIV and TB form a lethal combination, each speeding the other's progress if not treated. In 2017, about 0.3 million people died of HIV-associated TB. In the same year, about 40% of deaths among PLHIV were due to TB.

- Without proper treatment, 45% of HIV-negative people with TB on average and nearly all HIV-positive people with TB will die within 2 years.

- The programme mandates that people with HIV should be regularly tested for TB and all people diagnosed with TB should be tested for HIV.

- People with diabetes have an increased risk of active TB or TB disease (2-3 times higher than people without diabetes).

- For these reasons, it is essential that anyone diagnosed with TB is tested for diabetes regularly and vice-versa.

- There is some preliminary evidence to show that diabetes worsens TB treatment outcomes – increased deaths and relapse rates.

- For the affected individual, managing two infections can be difficult, and support from families and communities is essential.

SUPPORT REQUIRED:

- Like other long-drawn out illnesses, TB affects an individual in multiple ways. Apart from the physical symptoms, TB also has an effect on the earning capacity of an individual and patients are often not able to support their family.

- People affected by TB face a certain amount of stigma and risk being isolated or ostracised. Everyone should have access to diagnostic and treatment for free.

- Psycho-Social Support

◊ Counselling: Peer-counselling from TB survivors and/or people affected by TB can be very effective in providing support. Channels for open communication that allows information sharing, peer support, undertaking collective activities and problem-sharing should be established. This can be through meetings, app-based groups, phone calls or other preferred means. Peer counsellors need to keep in mind that issues that fall beyond their scope should be referred to professional counsellors and experts (for example: potential mental health issues, suicidal ideation, serious unaddressed medical complications, etc.)

◊ Social Support: During the course of treatment persons affected by TB need the support of family, friends, well-wishers and community members. A good support system can help prevent the patient from spiralling into depression and giving up the treatment. To avoid catastrophic costs, adequate financial support is essential for people who are diagnosed and on treatment for TB.

- Access to good nutritious food is also important during TB treatment.

CHILDHOOD TB

- 1 million children fall ill with TB each year. Children represent about 11% of all persons affected by TB.

- In 2015, 210,000 children died of TB, including 40,000 TB deaths among children who were HIV+.

- Estimates indicate that 67 million children are infected with TB (latent TB) and are at risk of developing disease.

- Researchers estimate that 25,000 children develop multidrug-resistant TB every year.

KEY CHALLENGES

- TB in children is often missed or overlooked due to non-specific symptoms and lack of a sensitive and child-friendly diagnostic test (not based on sputum).

- Healthcare workers and other health services often lack sufficient knowledge and capacity for prevention, diagnosis and management of childhood TB.

- Systematic screening for TB and isoniazid preventive therapy (IPT) for children under 5 years of age and children living with HIV are rarely implemented or reported.

- Lack of community knowledge and engagement.

- Until recently, no child-friendly formulations were available and there are no child formulations of second line TB drugs.

- The current TB vaccine (BCG) protects young children against the most severe forms of TB, but does not prevent the transmission of TB from an infectious contact.

RISK FACTORS

Living in a setting where there are people with TB or MDR TB -even if they are vaccinated.

- Vulnerable immune systems, such as the very young, HIV or severely malnourished.

- Infants and young children are at increased risk of developing severe disease associated with high mortality, such as TB meningitis or miliary TB.

- Adolescents are at particular risk of developing adult type disease, i.e. often sputum smear-positive and highly infectious.

- Poor and vulnerable communities that lack access to health care.

- Children develop TB disease usually within 1 year following infection. TB in children is an indicator of recent and ongoing transmission of MTB in the community.

DAY 1
SESSION 3
PREVENTION

SESSION 3: PREVENTION

Duration: 30 minutes

Training Aids/Materials Required:

- PowerPoint slides

- Laptop

- LCD projector

- Handout-B and Handout-C

Learning Objectives: By the end of this session, participants will be able to identify the methods of TB prevention and describe Latent TB Infection (LTBI).

METHODOLOGY

Step 3.1: Understanding TB Prevention (5 min)

- Ask participants to share what they know of methods to prevent TB.

Facilitators' Note:

This could include:

- Cough etiquette

- No spitting

- Wearing a mask

- Cross-ventilation

- Size of room or living space

- Duration of exposure

- Sunlight or ultraviolet (UV) light

The BCG (Bacille Calmette Guerin) vaccine is currently the only vaccine available for TB. This is a weakened strain of TB that encourages the body to build immunity against the disease. BCG only protects children from severe

forms of TB such as meningitis and disseminated TB. BCG also provides a moderate protective effect against leprosy.

Use the following discussion points to drive home the role of communities in TB prevention:

- Prevention requires mobilizing an entirely new group of people who are not yet ill (the pre symptomatically ill).

- Latent TB infection

- For example TB is a disease of families and communities. Taking TB preventive therapy is a way to "TB proof" your family or community against TB – just like you would fireproof a house.

- People who are diagnosed with active TB request contact tracing and screening of family and friends.

- PLHIV demand preventive therapy as their right.

- People see taking preventive therapy as making a choice to proactively protect their health and wellbeing.

Step 3.2: Latent TB Infection (15 min)

Explain latent TB infection, including population groups that should be considered for LTBI testing and treatment as well as groups that may be considered for the same. The session would also discuss the WHO guidance on medication for TB prevention.

- Latent tuberculosis infection (LTBI) is a state of persistent immune response to stimulation by Mycobacterium tuberculosis antigens without evidence of clinically manifested active TB. Someone has latent TB if they are infected with the TB bacteria but do not have signs of active TB disease and do not feel ill. However, they can develop active TB disease in the future.

- LTBI testing and treatment should be considered for the following groups (WHO guidelines):

  ▶ People living with HIV (PLHIV)

  ▶ All adults and adolescents living with HIV

  ▶ All infants and children living HIV

- ► Contacts

  Children < 5, regardless of HIV

  Adults and child contacts in low burden settings (LBC)

  - ► HIV-negative clinical risk groups: patients on anti- TNF, receiving dialysis, preparing for transplantation, and those with silicosis

- • LTBI testing and treatment may be considered for the following groups:

  - ► HIV-negative children ≥ 5, adolescents, and adults who are contacts in high-burden settings (HBC)

  - ► Contacts of patients with multidrug-resistant TB

  - ► HIV-negative prisoners, health workers, immigrants from HBCs, homeless persons, people who use illicit drugs, living in LBCs

  - ► Children living with HIV who have successfully completed treatment for TB

- • WHO LTBI Guidelines: Treatment

  - ► Isoniazid monotherapy for 6 months for adults and children in countries with high and low TB incidence

  - ► Rifampicin plus isoniazid daily for 3 months for children and adolescents aged <15 years in countries with high TB incidence

  - ► Rifapentine and isoniazid weekly for 3 months for both adults and children in countries with high TB incidence

  - ► In low incidence countries: 9 months isoniazid, 3 months weekly rifapentine plus isoniazid, 3 – 4 months rifampicin plus isoniazid, 3 – 4 months rifampicin alone

Step 3.3: Discussion (10 min)

Provide participants with Handouts C and D, briefly explaining its content. Invite questions and address concerns that participants may express.

HANDOUT - B

Frequently Asked Questions

[Updated and Consolidated Guidelines for Programmatic Management of LTBI: A Critical Action to Achieve the WHO End TB Strategy Targets]

1) What is latent TB?

Latent tuberculosis infection (LTBI) is a state of persistent immune response to stimulation by Mycobacterium tuberculosis antigens without evidence of clinically manifested active TB. Someone has latent TB if they are infected with the TB bacteria but do not have signs of active TB disease and do not feel ill. However, they can develop active TB disease in the future.

2) Why should I take pills to treat latent TB when I do not feel ill?

You have been asked to take treatment for latent TB because your health-care worker or clinician believes you have an increased chance of developing active TB disease from the infection. Effective drugs are available for the treatment of latent TB and taking a complete course of treatment can prevent the infection from becoming active disease.

3) Do I need to take TB preventive treatment if I am living with HIV and receiving ART, and have a high CD4 cell count?

All adults and adolescents living with HIV should take TB preventive treatment as part of a comprehensive package of care for HIV, regardless of their CD4 cell count. Although regular ART reduces the overall risk of developing TB among PLHIV, the risk remains very high compared to HIV-negative people. Combined use of TB preventive treatment and ART significantly reduces the risk of TB.

4) Should I receive TB preventive treatment if a person in my family has multidrug-resistant TB?

Please consult your health-care worker or clinician. The health-care worker or clinician will make the decision to provide preventive treatment in selected household contacts of patients with multidrug-resistant tuberculosis, if they are regarded as high-risk for developing drug-resistant TB.

5) What should I do if I develop drug-related adverse events?

If you are receiving treatment for latent TB, and become aware of symptoms such as anorexia, nausea, vomiting, abdominal discomfort, persistent fatigue or weakness, dark-coloured urine, pale stools or jaundice you should immediately contact your health care provider. If a health care provider cannot be consulted at the onset of such symptoms, you should stop treatment immediately and continue to seek help from your health care provider.

6) Who should receive testing and treatment for latent TB?

Adults, adolescents, children and infants living with HIV, infants and children < 5 years who are contacts of TB patients, and HIV-negative clinical risk groups, such as patients initiating anti -TNF treatment, receiving dialysis, preparing for organ or haematological transplantation have the highest likelihood of developing active TB disease and should be prioritized for systematic testing and treatment of LTBI, regardless of setting or the background TB epidemiology. Additional groups for LTBI testing and treatment are: HIV-negative children >5 years, adolescents and adults who are contacts of patients with pulmonary TB and contacts of patients with multidrug-resistant TB. Systematic testing and treatment of LTBI may be considered for HIV-negative prisoners, health-workers, immigrants from high TB burden countries, homeless persons and people who use illicit drugs, if living in low TB burden settings.

7) Should pregnant women living with HIV take TB preventive treatment?

Pregnant women living with HIV are at risk for TB, which can have severe consequences for both the mother and their unborn child. Pregnancy should

not disqualify them from receiving preventive treatment. Sound clinical judgment is required to determine the best time to provide treatment.

8) How can we rule-out active TB in PLHIV prior to TB preventive therapy?

Adults and adolescents living with HIV should be screened for TB according to a clinical algorithm and those who report any of the symptoms of current cough, fever, weight loss or night sweats may have active TB and should be evaluated for TB. Those with a negative symptoms screen are unlikely to have active TB and should be offered preventive treatment, regardless of their ART status. Chest radiography may be offered to people living with HIV who are receiving ART. If no abnormal radiographic findings are observed, preventive treatment can be given. However, chest radiography should not be considered a mandatory requirement or be a barrier to initiating TB preventive treatment in people living with HIV.

9) Which tests can be used to test for latent TB infection?

Either a tuberculin skin test (TST) or interferon gamma release assays (IGRA) can be used to test for LTBI. There is no strong evidence that one test should be preferred over the other to predict progression to active TB disease. The choice will depend on test availability, cost and the health infrastructure. However, neither the TST nor IGRA can be used to diagnose active TB disease nor for the diagnostic workup of adults suspected of having active TB. LTBI testing by TST or IGRA is not a requirement for initiating preventive treatment in people living with HIV or children aged < 5years who are household contacts with a pulmonary TB patient. The evidence reviewed and the recommendations in the 2018 consolidated guidelines apply to the use of QuantiFERON®-TB Gold In-Tube and T-SPOT®.TB only. Any new or generic test should be subjected to proper validation according to WHO guidelines.

10) What TB preventive treatment options are available?

Isoniazid or INH has been the standard treatment for LTBI. It works very well to prevent TB but it has to be taken daily for 6 to 9 months. It is usually given with vitamin B6 or pyridoxine. Rifapentine combined with isoniazid, also known as 3HP, is another regimen that is recommended as an alternative to

INH monotherapy for both adults and children. 3HP is taken once a week for 12 weeks. Isoniazid plus rifampicin for 3 months (3RH), is recommended for children and adolescents <15 as alternative to isoniazid in countries with a high TB incidence.

11) Should people living with HIV on ART receive rifapentine?

Regimens containing rifamycins such as rifampicin and rifapentine should be prescribed with caution to people living with HIV who are on ART because of potential drug-drug interactions. These regimens should not be administered to people receiving protease inhibitors or nevirapine. The 3-month regimen of weekly rifapentine plus isoniazid can be administered to patients receiving efavirenz-based antiretroviral regimens without dose adjustment. Administration of rifapentine with raltegravir was found to be safe and well tolerated. Rifapentine-containing regimens should not be administered with dolutegravir until more information becomes available from ongoing studies.

12) Should TB preventive treatment be provided by direct observation of treatment (DOT)?

All TB preventive treatment options can be self-administered. The selection of treatment options by programmes and clinicians should consider the best modality for treatment provision and monitoring, considering client preference and to ensure that treatment is not only initiated but also completed.

13) Should the course of TB preventive treatment be repeated?

There is no evidence about repeated courses of preventive treatment, and hence no recommendation is made in the present guidelines. However, in settings with high TB transmission (as defined by local authorities), isoniazid for 36 months (as a proxy for lifelong therapy) is recommended for PLHIV.

14) What can be done to encourage treatment adherence and support completion of TB preventive treatment?

Interventions should be tailored to the specific needs of the risk groups and to the local context to ensure adherence and completion of treatment. Such interventions could include peer support, coaching and educational interventions. Further interventions to support adherence are mentioned in the WHO Guidelines on the treatment of drug susceptible TB, which could be applied to the treatment of LTBI. Shorter latent TB treatment regimens are associated with better adherence and higher treatment completion. Concerns about adherence should, however, not be a barrier to nationwide scale-up of TB preventive treatment.

15) Is it necessary to do testing of baseline liver function?

There is insufficient evidence to support mandatory or routine testing of baseline liver functions. However, where feasible, baseline testing is strongly encouraged for individuals with the following risk factors: history of liver disease, regular use of alcohol, chronic liver disease, HIV infection, age > 35 years, pregnancy or in the immediate postpartum period (within 3 months of delivery). For individuals with abnormal baseline test results, sound clinical judgment is required to ensure that the benefit of TB preventive treatment outweighs the risks. Moreover, these individuals should be tested routinely at subsequent visits. Appropriate laboratory testing should also be performed for patients who become symptomatic while on treatment (e.g. liver function tests for those with symptoms of hepatotoxicity).

16) Will implementation of TB preventive treatment worsen the TB drug-resistance problem?

There is no evidence of a significant association between TB drug-resistance and the use of INH or rifamycins for the treatment of LTBI. Nonetheless, active TB disease must be excluded before TB preventive treatment is prescribed, and regular follow-up is required to ensure that people who develop active TB while receiving TB preventive treatment could be identified early. It would be desirable for countries implementing programmatic management of LTBI to establish national surveillance systems for resistance to TB drugs.

HANDOUT - C

Latent Tuberculosis Infection

Key Facts[3]

Latent tuberculosis infection (LTBI) is a state of persistent immune response to stimulation by Mycobacterium tuberculosis antigens without evidence of clinically manifested active TB.

Someone has latent TB if they are infected with the TB mycobacteria but do not have signs of active TB disease. Although individuals with LTBI do not have active TB disease, they may develop disease in the future, making the person ill and putting them at risk of passing the infection to other people.

A quarter of the world's population is estimated to have LTBI. Systematically providing TB preventive treatment to those at highest risk of developing active TB will prevent the development of disease and also reduce the risk of transmission in the population; this is critical to End TB locally and worldwide.

In 2017, around 1 million people living with HIV (PLHIV) and around 300,000 child household contacts < 5 were provided with preventive treatment.

TB preventive treatment is a key component of the End TB strategy, and TB preventive treatment coverage among those eligible is one of the top 10 indicators to monitor progress. Implementation is currently suboptimal but opportunities for scale-up abound. WHO estimates that approximately 30 million people*, including people living with HIV and all household contacts of TB patients, regardless of age, would need to be provided TB preventive treatment between 2018-2022.

DAY 1

SESSION 4

TB AND ME

SESSION 4: TB & ME

Duration: 1 hour

Training Aids/Materials Required:

- Flipchart/whiteboard

- Coloured markers

- Audio of soothing music

Learning Objectives: By the end of this session, participants will be able to identify crucial issues faced by persons affected by TB that necessitate the community's response as agents of change.

METHODOLOGY

Facilitators' Note:

Preparation: Prior to the commencement of this session, do identify participants who will be sharing their stories, brief them on the purpose, content and duration of this exercise and take their consent to document the stories that they have shared.

Step 4.1: Story Telling

Invite 4-5 participants to share their experiences of real life incidents related to TB, its social aspects and treatment accessibility. Participants will be provided with 5 minutes to tell their stories.

Step 4.2: Discussion

Ask other participants to comment on what aspects of the stories were most significant. Note the key issues from the sharing that identify potential change agents on a flipchart/whiteboard and summarize.

Facilitators' Note:

Take 10 minutes to play some soothing music, show a short video demonstrating relaxation techniques or perform some relaxation exercises as a group.

If possible, arrange for a counselor to be present at the session to address any counselling needs that may be required.

DAY 1

SESSION 5
COMMUNITY ENGAGEMENT 101

SESSION 5:
COMMUNITY ENGAGEMENT 101

Duration: 45 minutes

Training Aids/Materials Required:

- Flipchart/sheets of chart paper

- Coloured markers

- Handout-D

Learning Objectives: By the end of this session, participants will be able to illustrate the meaning and rationale of community engagement.

METHODOLOGY

Step 5.1: Getting on the Same Page

Ask participants to suggest words or terms that may be used to describe a community. This could include terms in the context of general communities as well as those associated with persons affected by TB. Note the responses on a flip chart or white board.

Explain

- The term 'community' is widely interpreted in many ways. For our understanding, 'community' is used to refer to a group of people, defined by some common characteristics.

- The phrase 'affected community' is specifically used to refer to those who have been directly affected by a disease. This could include, for example, someone living with TB as well as his/her family or someone being treated for TB.

- Inadequately served populations refer to people who are vulnerable, underserved or at-risk of TB infection and illness. This could include people living with HIV, people who use drugs, people who have increased exposure to TB due to where they live or work, people who have limited access to quality TB services, and people at increased risk of TB because of biological or behavioral factors that compromise immune function.

Step 5.2: Service Mapping – Group Exercise

This exercise will help to identify the services exist and are accessed (or not easily accessed) by the community of people affected by TB. This will be helpful in helping participants understand the role of community engagement in improving access to services.

1. Explain the purpose of the tool and ask participants to work in groups formed on the basis of the geographical areas that they represent. (If participants represent a wide range of geographical areas, ask them to select a representational area for the exercise.)

2. Ask them to draw maps showing where different TB-related health facilities are located – formal and informal, modern and traditional.

3. Request them to identify:

   a. What services are available?

   b. Which ones they use and don't use and explain why

   c. Which services are most effective and why?

   d. Which services need improving or are missing altogether?

4. The maps are posted on the wall and other participants gather around each of the maps in turn while group members present the key points from their discussions.

Step 5.3: Discussion

Invite participants to share their thoughts on the need for community engagement in making services for TB more accessible

Facilitators' Note:

Supplement the discussion with the following points:

- Community engagement is defined as the process of working collaboratively with and through communities to address issues affecting their well-being.

- Empowering communities is key to a robust and sustained community engagement programme – communities need the right information in order to participate in the TB response.

- The involvement of communities can:

  ◊ Ensure engagement with policymakers and implementers to ensure justice, rights and dignity of TB patients for effective service delivery.

  ◊ Supplement and complement government initiatives to enforce TB patient- friendly law, policy and programs.

  ◊ Help reduce stigma and discrimination and ensure social security of TB patients, survivors and their families.

  ◊ Increase the social acceptance of those affected by these diseases.

  ◊ Break down the barriers/silence around issues of people living with TB.

  ◊ Bring the perspective of affected populations and people living with disease to the programmes.

Note: Please distribute feedback forms for Day 1.

HANDOUT - D

Inadequately Served Populations for TB[4]

People who have
INCREASED EXPOSURE
to TB
due to where they
live or work

Prisoners, sex workers, miners, hospital visitors,
health care workers and community health workers

PEOPLE WHO:
- live in urban slums
- live in poorly ventilated or dusty conditions
- are contacts of TB patients, including children
- work in environments that are overcrowded
- work in hospitals or are health care professionals

People who have
LIMITED ACCESS TO QUALITY TB SERVICES

Migrant workers, women in settings with gender disparity, children, refugees
or internally displaced people, illegal miners, and undocumented migrants

PEOPLE WHO:
- are from tribal populations or indigenous groups
- are homeless
- live in hard-to-reach areas
- live in homes for the elderly
- have mental or physical disabilities
- face legal barriers to access care
- are lesbian, gay, bisexual or transgender

People at
INCREASED RISK
of TB because
of **biological or behavioural factors**
that compromise
immune function

PEOPLE WHO:
- live with HIV
- have diabetes or silicosis
- undergo immunosuppressive therapy
- are undernourished
- use tobacco
- suffer from alcohol-use disorders
- inject drugs

People Who Use Drugs

Drug use has been linked to a higher incidence of both latent TB and active
TB disease. The increased risk of infection is due in part to the physiological
effects of drug use, especially opiates, in terms of compromised immunity. In
addition, people who use drugs are at risk for a variety of environmental and
behavioural factors that tend to coexist with drug use, such as homelessness,
tobacco and alcohol use, imprisonment, and risk of HIV and hepatitis C from
infected needles.

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4   Stop TB Partnership, UNOPS. 2015. Global Plan to End TB. The Paradigm Shift: 2016-2020

The effects of drug use can also mean that people do not access health services at critical junctures, such as for TB diagnosis and treatment immediately after HIV diagnosis. Even when people who use drugs do have access to TB care, they may have difficulty complying with a complicated or lengthy TB drug regimen. Moreover, opiates may suppress telltale TB symptoms such as persistent cough.

Integrating TB treatment with drug addiction therapy can help reach the most vulnerable, so long as TB treatment continues after drug rehabilitation. Psychosocial support and day hospitals could greatly increase the rate of treatment adherence. Because close contacts are at higher risk, TB infection can often spread among groups of people using drugs together. Therefore, interventions targeted at these populations must include TB preventive therapy.

People Living with HIV

TB is the most common cause of death in people with living with HIV. High rates of TB and HIV co-infection are a major challenge to driving down TB incidence in many countries. An estimated 0.9 million people worldwide living with HIV fall ill with TB every year. Among people with latent TB infection, people living with HIV are up to 30 times more likely to develop TB disease. People living with HIV are often subject to stigma and discrimination, which can prevent them from accessing services.

The Global Plan to End TB: The Paradigm shift: 2016-2020 calls for countries to find at least 90% of all people with TB in the population that require treatment (including those living with HIV) and place them on appropriate therapy (including TB treatment and preventive therapy for people living with HIV).

[Adapted from: Stop TB Partnership, UNOPS. 2015. Global Plan to End TB. The Paradigm Shift: 2016-2020]

DAY 2
SESSION 6: TB AND STIGMA

Duration: 45 minutes

Training Aids/Materials Required:

- Flipchart

- Sheets of chart paper

- Coloured markers

- PowerPoint presentation

- Laptop

- LCD projector

Learning Objectives: By the end of the session participants will be able to illustrate the causes, actions and consequences of stigma at all levels of the society; and identify relevant methods to address stigma and discrimination.

METHODOLOGY

Step 6.1: 'Let's grow a Tree' – Group Activity

Divide participants into groups comprising 6 to 7 members each. Provide each group with a flip chart and marker pens.

Instruct each group to draw a tree and list down the following as different parts of the tree:

- Roots: Root causes of stigma

- Trunk and Branches: Actions of stigma

- Fruits or Flowers of the Tree: Consequences of stigma

Step 6.2: Presentation of Group Work

Each group is given 2-3 minutes to present key points of their discussions, clearly identifying the causes, actions and consequences of stigma.

Step 6.3:

OPTION 1: SUMMARIZE

Consolidate the common findings from the group presentations and reinforce these with the aid of the following discussion points:

- What is Stigma?

Stigma can be defined as a mark of shame, disgrace or disapproval which results in an individual being rejected, discriminated against and excluded from participating in a number of different areas of society. (WHO)

- Causes of Stigma

1. Myths and misconceptions	6. Homelessness
2. TB as a result of witch craft	7. Person's history of prison or refugee status
3. TB is regarded as poor man's disease	8. HIV status
4. Lack of education on TB and its modes of transmission	9. Gender roles
5. Drugs and alcohol use	

- Consequences of Stigma

1. Low self esteem	7. Less economic opportunities
2. Social exclusion	8. Reluctant to treatment and adherence
3. Feeling of guilt	9. Self stigma
4. Isolation	10. Suicidal tendency
5. Decreased quality of life and social status	11. Negative attitude and behavior
6. Non-disclosure	

OPTION 2:

Role Play

- Be clear about the objectives of the role play. Ask participants to prepare an outline of a situation/script that they would like to act out. (Alternately, write a situation beforehand and include brief details of the roles and situation for participants to act out).

- Ask for volunteers to act out the situation and give them 10-15 minutes to prepare.

- As the role play is performed, encourage other participants to watch and listen carefully.

- After the role play, ask the volunteers what it was like to act the parts, what they learned and how they felt. Then, ask the other participants how they felt while watching the role play and what they learned and how they felt.

- Encourage participants to discuss the following:

  ◊ What were the challenges of the situation?

  ◊ What might have been the effects of the situation?

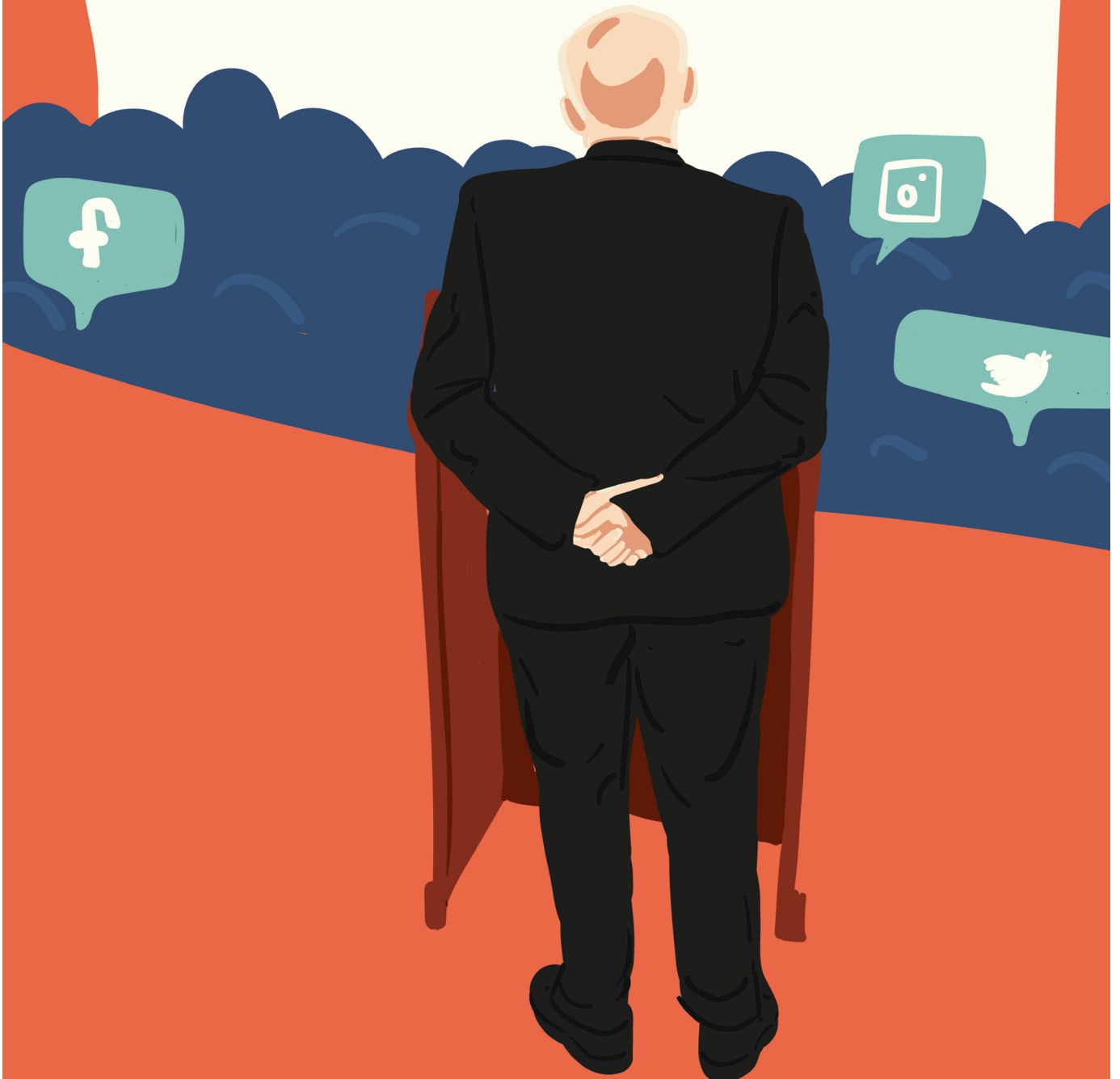 ◊ What could have made the situation better?

Facilitators' Note:

Make a note on the major consequences of stigma on a flipchart and build on these points during the session on advocacy.

DAY 2

SESSION 7

ADVOCACY BASICS

SESSION 7: ADVOCACY BASICS

Duration: 1 hour 30 minutes

Training Aids/Materials Required:

- Flipchart

- Coloured markers

- PowerPoint presentation

- Laptop

- LCD projector

Learning Objectives: At the end of this session participants will be able to define advocacy, list the steps of advocacy, differentiate between the types of advocacy and describe various advocacy tools.

METHODOLOGY

Facilitators' Note:

The steps of this session may be adapted to suit the profiles of the participants. For instance, participants who already have some experience of advocacy may start from Step 7.3

Step 7.1: Understanding Advocacy - Brainstorming

Ask participants to take a moment to reflect on the term 'advocacy' and ask them to provide one word each that best defines advocacy. Make a note of the terms that emerge and supplement with the following standard definitions of advocacy:

- ▶ Advocacy denotes activities designed to place the TB response high on the political and development agenda, foster political will, increase financial and other resources on a sustainable basis, and hold authorities accountable to ensure that pledges are fulfilled, and results are achieved.

► Advocacy often focuses on influencing policy-makers, funding agencies and international decision making bodies through a variety of channels: conferences, summits and symposia, celebrity spokespeople, meetings between various levels of government and civil society organizations, news coverage, official memoranda of understanding, parliamentary debates and other political events, partnership meetings, patients' organizations, press conferences, private physicians, radio and television talk shows, service providers.

Facilitators' Note:

While several definitions for advocacy exist, this definition fits our need and is in keeping with existing UN advocacy definitions.

Advocacy denotes activities designed to place the TB response high on the political and development agenda, foster political will, increase financial and other resources on a sustainable basis, and hold authorities accountable to ensure that pledges are fulfilled, and results are achieved.

Step 7.2: Types of Advocacy

Differentiate between the two main types of advocacy: reactive and proactive advocacy, with the help of the following discussion points:

- Reactive: Reactive advocacy is based on responding to events after they have happen

- Pro-active: A pro-active approach focuses on eliminating problems before they have a chance to appear

Ask participants to suggest examples from their own experiences on the types of advocacy that they have been involved in (or have heard about) and identify whether they were reactive or proactive.
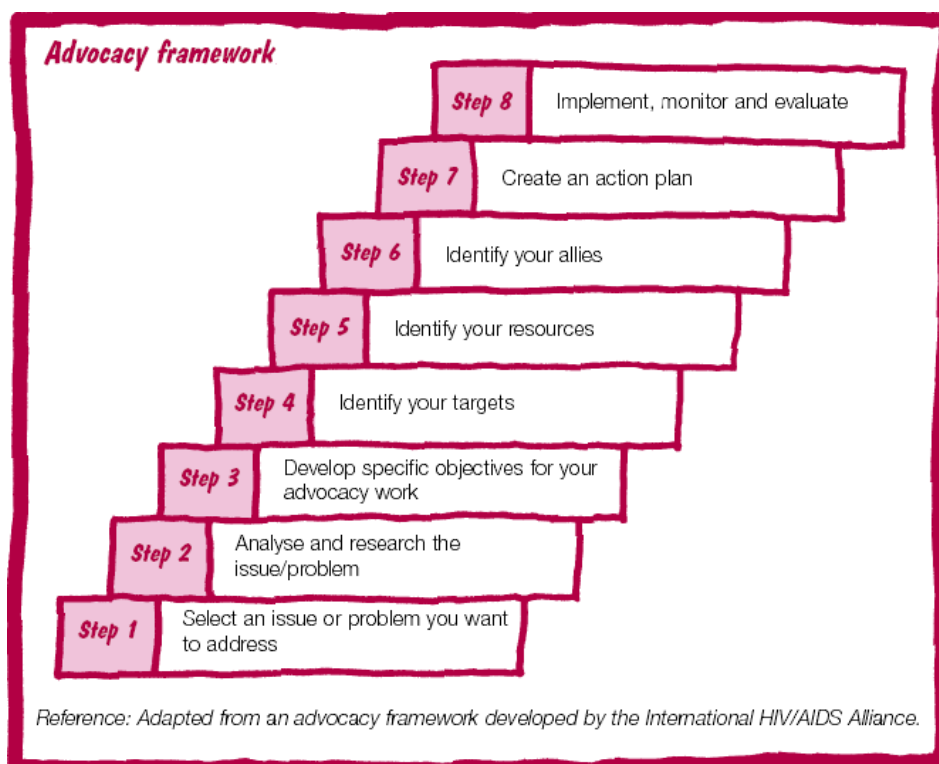
Facilitators' Note:

Share a practical example of reactive and proactive advocacy to illustrate the difference between the two types of advocacy.

Advocacy can take on various forms such as:

- Policy Advocacy: Informs politicians, etc. how an issue will affect the country; requests specific actions to improve laws and policies.

- Program Advocacy: Targets opinion leaders at the national/community level to take action.

- Media Advocacy: Validates the relevance of a subject; puts issues on the public agenda, prompts the media to cover TB-related topics.

Step 7.3: Steps of Advocacy

Discuss the following suggested framework for advocacy:

Advocacy framework

Step 8	Implement, monitor and evaluate
Step 7	Create an action plan
Step 6	Identify your allies
Step 5	Identify your resources
Step 4	Identify your targets
Step 3	Develop specific objectives for your advocacy work
Step 2	Analyse and research the issue/problem
Step 1	Select an issue or problem you want to address

Reference: Adapted from an advocacy framework developed by the International HIV/AIDS Alliance.

Facilitators' Note:

An alternative method would be to note the steps incrementally on a flipchart and pause between steps to explain the details. The Advocacy Framework may be provided to participants as a handout.

Walk the participants through each step of the process:

1. Select an issue of problem you want to address

    - Prioritize the most urgent issue requiring advocacy, for which you have the appropriate resources and knowledge.

    - Discuss why you want to take up the issue and what you hope to achieve.

2. Analyze and research the issue/problem

    - Gather as much information about the issue as possible.

    - What are the key areas you want to focus on? Are there existing advocacy efforts to address these? How much documented evidence is available?

    - What kind of evidence can be used for advocacy? Photographs, testimonies, official records, correspondence, etc.

    - How can these be used?

3. Develop specific objectives for your advocacy work

    - Objectives should be clear and focused.

    - Should be a specific statement that clearly describes results that will be pursued within a specific period (Specific, Measurable, Achievable, Realistic and Time-bound).

4. Identify your targets

    - Primary target audience includes decision makers who have authority to bring about desired change.

    - Secondary target audience includes persons who have access to and are able to influence primary target audience – like other policy makers, community leaders, friends, relatives, media, religious leaders, etc.

    - Identify individuals in the target audience and their positions – determining whether they support, oppose or are neutral to the advocacy issue.

5. Identify your resources

   - Resources can include people and funds – not all advocacy initiatives require funding.

   - What are the internal resources you have? Can you also access external resources?

6. Identify your allies

   - Potential allies may include other organisations or community groups.

   - Building a wide support base is essential, as is working in collaboration with other partners – can help pulling together resources, approaching decision makers and rallying supporters.

7. Create an action plan

   - Put together an action plan to guide the advocacy process. This should include details of activities, timelines and allocation of responsibilities.

8. Implement, monitor and evaluate

   - Build in monitoring and evaluation as an ongoing component to the advocacy strategy.

   - Periodically review each step in your plan and determine whether it was implemented effectively, or if course corrections are required.

Step 7.4: Advocacy tools

Take the participants through the various possible tools of advocacy. These tools include:

▶ Information: Gathering, managing and disseminating information lays the basis for determining the direction of an advocacy campaign. Research is one way of gathering information.

▶ Research: Conducting research and policy analysis uses the information from various sources and develops it into policy options which become the key content of an advocacy campaign.

▶ Media: Various media are used to communicate the campaign's message(s) to the different stakeholders.

▶ Social Mobilization: Mobilizing the broadest possible support from a range of stakeholders, including the public at large, is essential to building the influence of the campaign.

▶ Influencing: Convincing the decision-makers who have the power to make the desired change involves a set of special knowledge and skills.

▶ Litigation: Sometimes, using the court system to challenge a policy or law can reinforce an advocacy campaign.

▶ Networks, Alliances and Coalitions: Sharing of information and resources, and strength in unity and commonality of purpose are key to the success of advocacy work.

Facilitators' Note:

These could translate into actions that the community could take up, such as:

- Hold a public panel discussion

- Arrange face-to-face meetings with advocacy targets

- Arrange a phone call in

- Write letters and emails to decision-makers

- Write a petition

- Use social media platforms such as blogs, Twitter, Facebook and WhatsApp

- Use audio-visual media

- Organize a media stunt or public protest

- Write a press release

- Organise rallies

- Hold a press conference

- Call for cease of local business and transportation

Facilitators' Note:

Provide a few tips on what should be kept in mind while developing advocacy strategies or conducting advocacy initiatives.
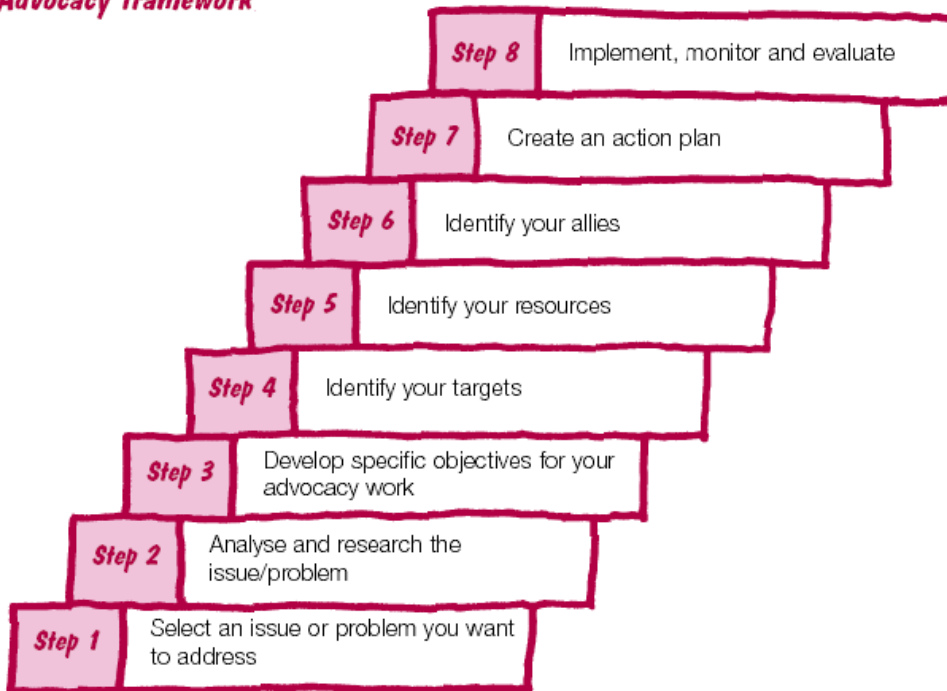
ADDITIONAL RESOURCES

- Advocacy is a process to bring about change in the policies, laws and practices of influential individuals, groups and institutions.

- Advocacy is a process of change- a series of activities linked to a defined goal – and not just a one-off event.

- Advocacy consists of more than one strategy or activity. It entails the implementation of various strategies and activities over time, with creativity and persistence.

- Advocacy victories often are preceded by numerous failures. It is important not to give up, but to learn from our mistakes and to continually strengthen an organization in terms of its social power and technical capacity.

- Advocacy combines various complementary initiatives in order to achieve an objective. Advocacy influences policy-makers, funders and decision-makers; variety of channels. It seeks to ensure that governments are committed to implementing TB control policies and activities.

- Advocacy can take many forms. In relation to TB, it could for example be:

    ◊ a coalition of civil society organisations (CSOs) holding a press conference or jointly signing an open letter;

    ◊ a meeting with a country's President;

    ◊ a drama about rights performed for key decision-makers by actors living with TB.

Advocacy can be written, spoken, sung or acted. It can also vary in the time it takes – from a few minutes to several years. We can do advocacy on our own or with others. It is possible to advocate for other people or for our own selves.

HANDOUT - E

Advocacy framework

Step 8 — Implement, monitor and evaluate

Step 7 — Create an action plan

Step 6 — Identify your allies

Step 5 — Identify your resources

Step 4 — Identify your targets

Step 3 — Develop specific objectives for your advocacy work

Step 2 — Analyse and research the issue/problem

Step 1 — Select an issue or problem you want to address

Reference: Adapted from an advocacy framework developed by the International HIV/AIDS Alliance.

SESSION 8:
STAKEHOLDER ANALYSIS

Duration: 1 hour

Training Aids/Materials Required:

- Flipchart

- Sheets of chart paper

- Post-it notes

- Coloured markers

- PowerPoint presentation

- Laptop

- LCD projector

Learning Objectives: By the end of this session, participants will be able to identify relevant stakeholders and illustrate the advocacy approaches to be used for different stakeholders according to varying levels of influence

METHODOLOGY

Step 8.1: Understanding Our Stakeholders

Facilitate an open discussion about the different kinds of people and institutions that the community of people affected by TB can and should work with, based on the following discussion points:

- Who are Stakeholders?

'Stakeholders' are persons or groups who have an interest in our project or campaign.

- Objective of Stakeholder Analysis ?

To map the importance of the issue to each stakeholder and their level of influence.

Step 8.2:

OPTION 1

Stakeholder Mapping – Group Exercise

Divide participants into groups consisting of 6-7 members in each group. Provide each group with a flip chart/chart paper and permanent markers.

- Identify Your Stakeholders: Start by brainstorming who the stakeholders are. Ask participants to make a list (on separate post-it notes) of all the people who are affected by their work, how have influence or power over it, or have an interest in it.

Facilitators' Note:

Stakeholders can be both organizations and people, but it is important to identify the correct individual stakeholders within a stakeholder organization.

- Prioritize Your Stakeholders: Ask group members to map out their stakeholders according to their power and interest in the grid below (sheets of chart paper may be provided to each group).

The Power/Interest Grid may be projected on the screen or reproduced on a flipchart for quick reference.

Power/Interest Grid for Stakeholder Prioritization:
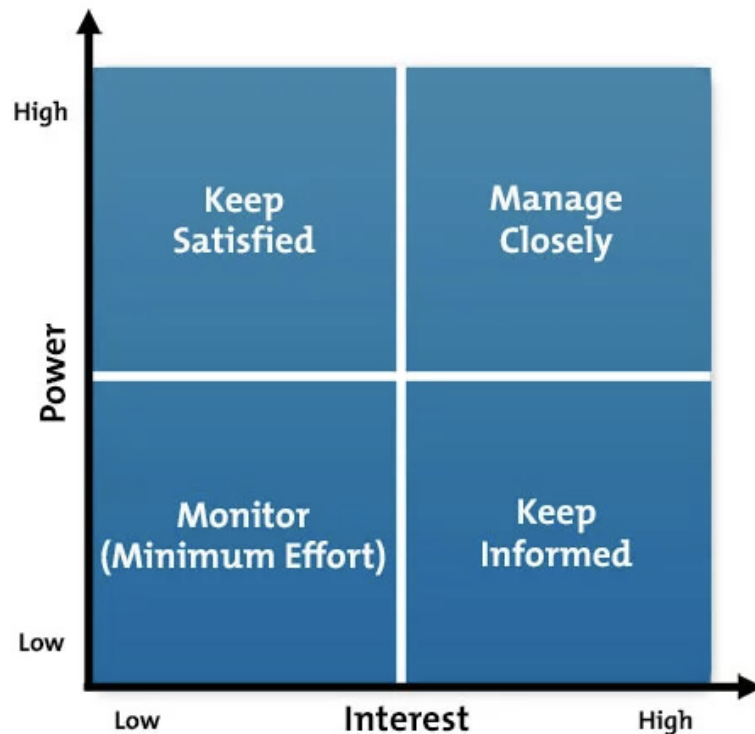
Explain: The position that you allocate to a stakeholder on the grid shows you the actions you need to take with them:

◊ High Power, Highly Interested People (manage closely): You must fully engage these people and make the most efforts to keep them satisfied.

◊ High Power, Less Interested People (keep satisfied): Put enough work in with these people to keep them satisfied, but not so much that they become bored with your message.

◊ Low Power, Highly Interested People (keep informed): Adequately inform these people and talk to them to ensure that no major issues arise. People in this category can often be helpful with your project.

◊ Low Power, Less Interested People (monitor): Again, monitor these people but don't bore them with excessive communication

- Understand your stakeholders: Participants need to work out how best to engage key stakeholders and how to communicate with them.

Facilitators' Note:

- Key questions that can help you understand your stakeholders include:

- What financial or emotional interest do they have in the outcome of your work? Is it positive or negative?

- What motivates them most of all?

- What information do they want from you and what is the best way of communicating with them?

- What is their current opinion of your work?

- Who influences their opinions generally, and who influences their opinion of you? Do some of these influencers therefore become important stakeholders in their own right?

- If they aren't likely to be positive, what will win them around to support your project?

- If they don't think that you'll be able to win them around, how will you manage their opposition?

- Who else might be influenced by their opinions?

OPTION 2

Power Pyramid (Stakeholder Analysis)

Divide participants into groups and provide them with flipcharts/chart paper and permanent markers. Ask each group to draw a triangle divided into 3 levels.

Group members are asked to first list all relevant stakeholders and then come to a consensus on assigning each of the stakeholders to the appropriate levels in the pyramid according to the following sequence:

- Bottom Level: least influential

- Mid-Level: fairly influential

- Top Level: most influential
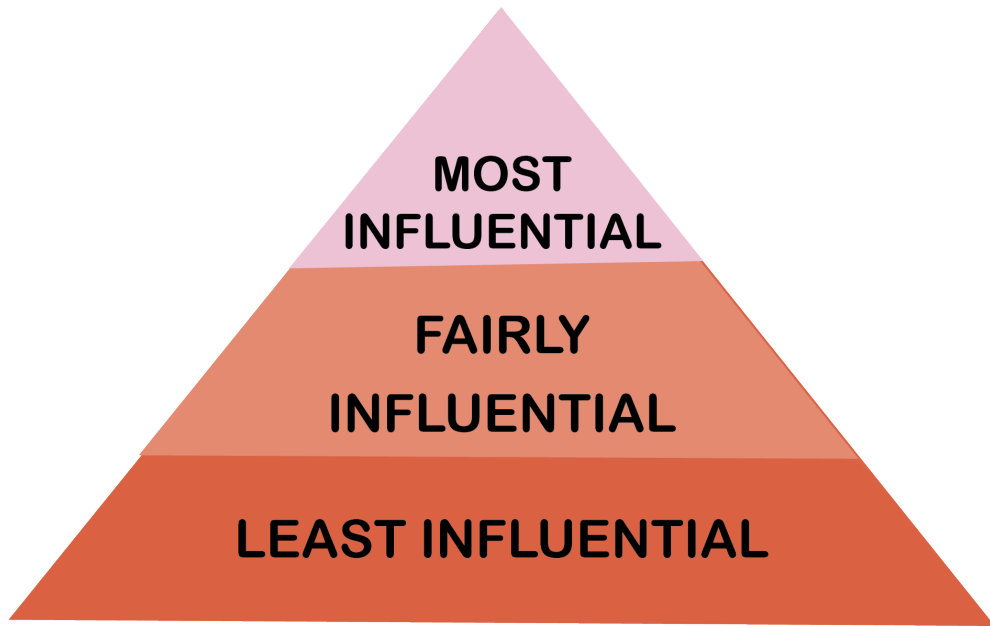
Step 8.3: Addressing Stakeholders

- Revisit the advocacy tools described in the previous session on advocacy and ask participants to discuss which tools can be used for different levels of stakeholders identified. The following template may be used as an example:

Key stakeholders	
Appropriate tools	
Key message(s)	

- Ask one spokesperson from each group to present a brief report on the group work to the larger group. Do ask participants to comment on the presentations made by other groups.

Step 8.4: Summarize

Consolidate the key points discussed in the session.

DAY 2

SESSION 9

COMMUNICATION-USE OF SOCIAL MEDIA

SESSION 9: COMMUNICATION - USE OF SOCIAL MEDIA

Duration: 1 hour

- Training Aids/Materials Required

- LCD projector and laptop

- Flipchart/white-board

- Colored white-board markers/pens

- Chart paper and colored pens

- Cue cards/post-its

- Handout F

- Reward for winners

Learning objectives: By the end of this session participants will be able to describe how digital space can be used for advocacy; and differentiate between various social media tools

METHODOLOGY

Step 9.1: Brainstorming (10 minutes)

Ask participants to suggest words that come to mind when we think of communication. Note these on a flip chart to demonstrate the range of perspectives to communication.

Share the following points:

- Being able to communicate effectively is the most important of all life skills.

  ◊ Communication is simply the act of transferring information from one place to another, whether this be:

  ◊ Vocally/verbally (using voice)

◊ Written (using printed or digital media such as books, magazines, websites or emails)

◊ Visually (using logos, maps, charts or graphs)

◊ Non-verbally (using body language, gestures and the tone and pitch of voice)

- How well this information can be transmitted and received is a measure of how good our communication skills are.

Step 9.2: Game 'Jump and earn' (10 minutes)

Ask the participants to line up on one end of the room and proceed to ask them true or false questions about social media platforms and ask them to jump towards the right if they think the answer is true and jump towards to left if the answer is false.

Facilitators' Notes:

- Prepare a set of 8 – 10 true/false questions on simple facts about social media. [Refer to Annex 1 for a set of suggested questions]

- Audio-visual aids maybe used to make the game more interesting

- Allocate points for every correct answer and hand out a prize at the end of the game

Step 9.3: Build on This Knowledge (30 minutes)

Begin by introducing why social media can be a best-buy for advocacy. Further, discuss the basics of choosing and using any social media platform with the aid of Handout F.

Step 9.4: Group work (10 minutes)

Divide the participants into groups of 4.

- Ask the groups to discuss and write down a key digital communication challenge that they face on a post-it.

- Ask the groups to pass the post-it to their left.

- Ask the groups to reconvene and brainstorm to provide a solution for the challenge presented to them.

- Ask one representative to read out the solutions for everyone.

- Give inputs as required.

Facilitators' Note:

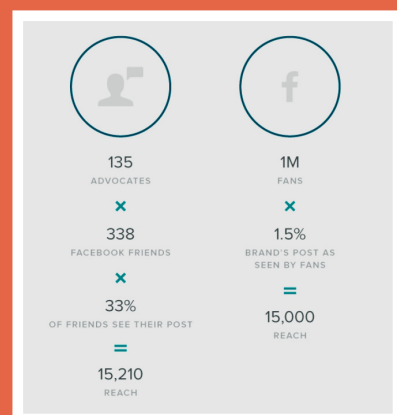Please distribute feedback forms for Day 2.

HANDOUT – F

What is Communication?

1. Communication is the process of imparting or interchanging of thoughts, opinions, or information by speech, writing, or signs[5].

2. Principals of Effective Communication for Health

   - Accessible – Map your stakeholders and tailor your communication channels to fit them.

   - Actionable - Messages should encourage decision-makers to take the recommended steps.

   - Credible - The action-makers should perceive your information to be credible. Use data points from reliable resources only.

   - Relevant – Communicate to help audiences to see the health information, advice or guidance as applicable to them, their families, or others they care about.

   - Timely – Communicate the right information at the right time.

   - Understandable – Communicate without jargon.

How to get maximum hits on Facebook?

   - Post regularly

   - Use images/ gifs/ memes/ videos

   - Keep it short

   - Add a link to all of your emails

   - Invite members and stakeholders to write on your wall

   - Use contests

   - Tell don't sell. Use the 80/20 Rule

135
ADVOCATES
×
338
FACEBOOK FRIENDS
×
33%
OF FRIENDS SEE THEIR POST
=
15,210
REACH

1M
FANS
×
1.5%
BRAND'S POST AS
SEEN BY FANS
=
15,000
REACH

- Make it personal, show your human side

How to get maximum traction on Twitter?

- Post regularly

- Use images/ gifs/ memes/ videos

- Re-use your top posts

- Use hashtags strategically

- Reply to mentions

- Make it personal, show your human side

  ◊ Build an in-house army of micro-influencers

People are 16x more likely to read a post from a friend than from a brand themselves.

FRIEND

BRAND
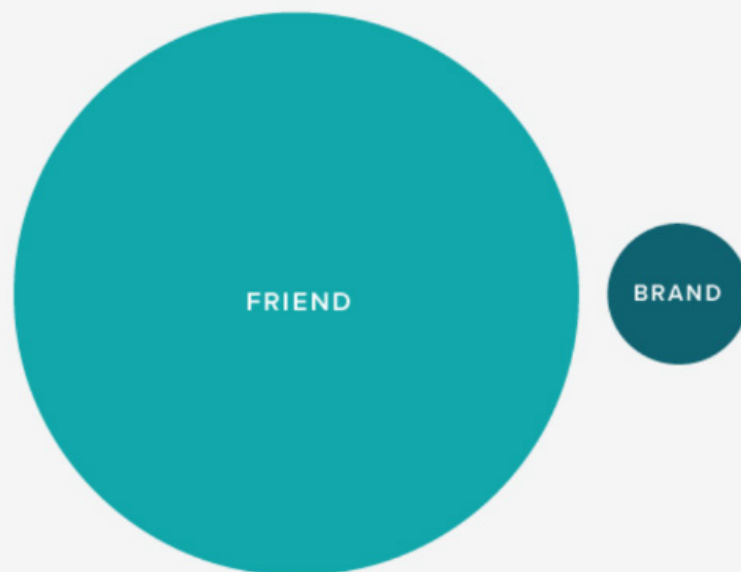
SESSION 10

DEVELOPING AN ADVOCACY PLAN

DAY 3
SESSION 10: DEVELOPING AN ADVOCACY PLAN

Duration: 1 hour

Training Aids/Materials Required:

- Flipchart

- Sheets of chart paper

- Coloured markers

- PowerPoint presentation

- Laptop

- LCD projector

- Handout-G

Learning Objectives: By the end of the session participants will be able to develop context-specific advocacy plans.

METHODOLOGY

Step 10.1: Walk the Talk

Divide participants into groups and give them 40 minutes to identify and agree on specific issues that require advocacy. Ask them to draw from the methods and techniques that have been discussed in the earlier sessions on stigma, advocacy tools and stakeholder analysis to develop an advocacy plan.

Facilitators' Note:

Handouts of the suggested template may be provided to participants.

The advocacy plan should address the following areas:

1. Issue(s) Identified for Advocacy

2. Advocacy Targets (stakeholders)

3. Objectives

4. Resources or Allies

5. Proposed Activities (tools that can be used to address the issue)

6. Timelines

7. Person(s) Responsible

8. Indicators

Step 10.2: Presentation of Group Work

Each group will present their plans at the end of the session. Feedback from other groups as well as the facilitator will be provided after each presentation.

Facilitators' Note:

Help participants to understand how to measure effectiveness of advocacy initiatives and come up with achievable indicators.

HANDOUT - G

Advocacy Plan Template

Issue	Targets	Objective	Resources/ Allies	Activities	Timelines	Person(s) Responsible	Indicators
(What's problem that you want to advocate for?)	(Who is it aimed at?)	(What change do you want to see?)	(Funds as well as people from other organizations or community groups)	(What do you want to do? What kind of tools can you use)	(When can you do it?)	(Who will do it?)	(How will we know that we are on the right track?)

DAY 3

SESSION 11

NEXT STEPS

SESSION 11: NEXT STEPS

Duration: 2 hours

Training Aids/Materials Required:

- Flipchart

- Sheets of chart paper

- Coloured markers

Learning Objectives: By the end of this session, participants will have developed individual action plans to carry forward their proposed actions as Change Agents

METHODOLOGY

Step 11.1: Discussion

Participants and representatives from GCTA will discuss the way forward and align proposed activities as per the overall workplan.

Facilitators' Note:

Do ensure that the action plans clearly reflect activities, people responsible, and periodic follow-up

Step 11.2: Closing

End the workshop with a note of thanks to the participants for their contributions.

Facilitators' Note:

If post-training self-assessment is to be conducted, please ensure that they are completed along with the feedback forms for Day 3.

ANNEX 1: PRE AND POST-TRAINING SELF-ASSESSMENT QUESTIONNAIRE

1. Community engagement helps in breaking down barriers around issues of people living with TB

a) True ☐

b) False ☐

2. TB affects only the lungs

a) True ☐

b) False ☐

3. TB is the most common opportunistic infection for people living with HIV

a) True ☐

b) False ☐

4. TB is a poor man's disease

a) True ☐

b) False ☐

c) Both ☐

5. Stigma is caused by lack of education on TB and its modes of transmission

a) True ☐

b) False ☐

6. Reactive advocacy is the only kind of advocacy that works

a) True ☐

b) False ☐

7. Advocacy is not just a one-off event

a) True ☐

b) False ☐

8. Stakeholders can refer to both individuals and institutions

a) True ☐

b) False ☐

9. Social media plays an important role in the TB response

a) True ☐

b) False ☐

10. LTBI has all the symptoms of TB

a) True ☐

b) False ☐

Answer codes:

1 – a	6 – b
2 – b	7 – a
3 – a	8 – a
4 – c	9 – a
5 – a	10 – b

ANNEX 2: GAME 'JUMP AND EARN' QUESTIONS

1. Social media is difficult to handle

   a. Allocate a point to all the participants for partaking in the game

2. Twitter is a micro-blogging platform

   a. True

3. A Facebook page and Facebook group are the same thing

   a. False

4. A Tweet can have maximum of 500 characters

   a. False

5. It is okay if I do not have frequent and periodic activity on my social media page

   a. False

6. You can edit a Tweet after you post it but you cannot do the same for a Facebook post

   a. False

7. More women use Facebook as compared to men

   a. True

8. Facebook caters to a larger market than Twitter

   a. True

9. Facebook is more popular with middle aged adults

   a. True

10. I do not have to engage with social media for advocacy

    a. Allocate a point to all the participants for partaking in the game. Move on to the next section of the session.

ANNEX 3: FEEDBACK FORMS

FEEDBACK FORM

Day-1

Sessions	Feedback Please place check mark (✔)			Remarks
	Good	Fair	Poor	
Session 1				
Session 2				
Session 3				
Session 4				
Session 5				

1. What did you learn during today's sessions that you anticipate using in your work?

2. Was there anything you did not like during today's sessions? Please provide specific examples.

3. Please provide any other comments or suggestions

Thank you.

FEEDBACK FORM

Day-2

Sessions	Feedback Please place check mark (✔)			Remarks
	Good	Fair	Poor	
Session 6				
Session 7				
Session 8				
Session 9				

1. What did you learn during today's sessions that you anticipate using in your work?

2. Was there anything you did not like during today's sessions? Please provide specific examples.

3. Please provide any other comments or suggestions

Thank you.

FEEDBACK FORM

Day-3

Sessions	Feedback			Remarks
	Please place check mark (✔)			
	Good	Fair	Poor	
Session 10				
Session 11				

1. What did you learn during today's sessions that you anticipate using in your work?

2. Was there anything you did not like during today's sessions? Please provide specific examples.

3. Please provide any other comments or suggestions

Thank you.

This manual is a living document – we are cognizant of the fact that there are a lot of ongoing developments in TB and the TB response landscape. We would like to keep updating the manual and would love to receive your feedback on your experience of using this manual.