Building the Capacity of Civil Society Organizations in TB Control - An Approach

3.2 Participants Manual
CSO Workshop

Contents

1. Goal and Objectives

Overall Goal
Strengthen participants' competencies to build their organizations' capacity enabling their role to contribute to TB control activities in their region.

Specific Objectives: Participants are able to:
1. Present their organization and make an organizational 'Strengths, Weaknesses, Opportunities and Threats' (SWOT) analysis
2. Present the basic information on tuberculosis (TB) symptoms, prevention, diagnosis and cure
3. Give an overview of the TB problems and infrastructure in their region
4. Map the stakeholders in TB control in their region, identify their roles and discuss how to improve collaboration among stakeholders
5. Discuss the stigma of TB and consequences for early detection and treatment adherence
6. Identify and discuss possible roles, tasks and responsibilities of Civil Society Organizations (CSOs) in TB control and CSOs' linkages with health care providers, the National TB Program (NTP) and patients
7. Establish their vision on patients' rights as human rights
8. Advocate for access to quality TB care in their region
9. Identify strategic target groups for TB health education and community mobilization
10. Communicate with specific target groups in an interactive way focusing on individual and collective behavioral change
11. Give an overview of funding possibilities for CSO activities in TB control, present the Global Fund (GF) mechanism and identify their organization's opportunities to participate in GF proposal writing
12. Facilitate the finalization of the CSO's action plan, its implementation and monitoring & evaluation.

2. Overview of Sessions

1. Introduction
Participants and Trainers present themselves
Participants' expectations
Training program and methodology

2. Your organization in progress
History, structure, members, staffing, funding
Activities and results
Strengths and challenges
Introducing action planning

3. TB and TB Control
What is TB, symptoms and causes of TB?
Diagnosis, treatment, costs of treatment
Prevention
Local burden of TB

4. Stakeholders in TB control
Who are the stakeholders in TB control?
What are their roles, tasks and responsibilities?
Collaboration among stakeholders and how to improve collaboration for improved TB control

5. **TB, Stigma and Human Rights**
   TB Stigma in different setting, forms, causes and effects
   Stigma, human and patients' rights
   Patient charter
   Actions to fight stigma

6. **TB Health Education**
   Target groups
   Health education for behavioral change
   Develop, implement and evaluate health education session

7. **Social Mobilization for TB control**
   Goal and target groups for social mobilization
   Identify new partners to be involved
   Steps for active involvement

8. **Advocacy for TB control**
   Advocacy: What and why
   Identifying advocacy messages and target groups
   Effective advocacy approach

9. **Funding for TB Control**
   Current funding sources of the CSOs
   Global Fund: mechanisms, organizations involved, planning and implementation,
   Challenge Facility and other smaller funding sources

10. **Annual Action Plan**
    Develop a draft annual plan to build the organization's capacity
    Develop a draft annual plan to implement TB control activities
    What support (from the mentoring organization and others) is needed in the finalizations and implementation of this plan?
    Monitoring and reporting of the Annual Action Plan

11. **Evaluation of the training course**
    Individual evaluation
    Evaluation per CSO

3. Training Methodology

The training is participatory and action oriented. We develop an open learning climate in which participants are active learners, share experiences and learn from each other and from the trainers. Activating training methods are used to enhance participants' participation and learning. At the end of the course participants will develop a draft annual action plan, integrating new insights they developed in the course. This action plan will be finalized and implemented in the coming year, with support of the mentoring organization.

4. Trainers

Your trainers for this course are:

5. Participants

From Mentee Organizations:

From Mentoring Organizations:

6. Training Program

Day	8.30-10.00	10.00 10.30	10.30 - 12.30	12.30 14.00	14.00 - 15.30	15.30 15.45	15.45 - 17.00
1.	8.30 - 9.30 **Session 1** Introduction of participants and program 9.30 - 10.00 **Session 2** Your organization in progress	**Coffee**	10.30-12.30 **Session 2** Your organization in progress (continued)	**Lunch**	14.00 - 15.30 **Session 3** TB and TB control	**Tea**	15.30 - 16.45 **Session 3** TB and TB control (continued) 16.45 - 17.00 Evaluation of the day
2.	8.30 - 8.45 Recap of the previous day 8.45 - 10.00 **Session 4** Stakeholders in TB control	**Coffee**	10.30 - 12.30 **Session 4** Stakeholders in TB control (continued)	**Lunch**	14.00 - 15.30 **Session 5** Stigma, Human and Patient Rights'	**Tea**	15.45 - 16.45 **Session 5** Stigma, Human and Patient Rights' (continued) 16.45 - 17.00 Evaluation of the day
3.	8.30 - 8.45 Recap of the previous day 8.45 - 10.00 **Session 6** Health Education	**Coffee**	10.30 - 12.30 **Session 6** Health Education (continued)	**Lunch**	14.00 - 15.30 **Session 7** Social Mobilization	**Tea**	15.45 - 16.45 **Session 8** Advocacy for TB control 16.45 - 17.00 Evaluation of the day
4.	8.30 - 8.45 Recap of the previous day 8.45 - 10.00 **Session 9** Funding in TB	**Coffee**	10.30 - 11.30 **Session 9** Funding in TB 11.30 - 12.30 **Session 10** Annual Action Plan	**Lunch**	14.00 - 15.30 **Session 10** Annual Action Plan	**Tea**	15.45 - 16.15 **Session 10** Annual Action Plan 16.00 - 17.00 **Session 11** Evaluation

7. Sessions

Session 1: Introduction

Session Objectives: Participants
- Know each other, the trainers and training program
- Have expressed their expectations

Assignment: Present yourself
- Name
- From which CSO
- Mentee or Mentoring Organization
- What is your function in the CSO?
- Who was the first person you met this morning?

Session 2: Your organization in progress

2.1 Session Objectives

The participants are able to:
- Present their organization
- Identify their organization's strengths, weaknesses, opportunities and threats
- Explain the need and focus of an organizational action plan

2.2 Assignment: Presenting Your Organization

Discuss the following questions with a diverse group of people working in your organization, including management, professional staff and volunteers. Write the results of the discussion on a flip chart and present this during the training.

A. Present your organization

Prior to the training, every Mentee CSO has prepared a poster to present its organization addressing the following issues:

1. When did your organization start?
2. What is your organization's main goal?
3. How many staff do you have?
4. How many of these staff are volunteers?
5. How is your organization funded?
6. What are your organization's key activities?
7. What are your organizations activities in the field of TB?

Also use visual materials to present your organization.

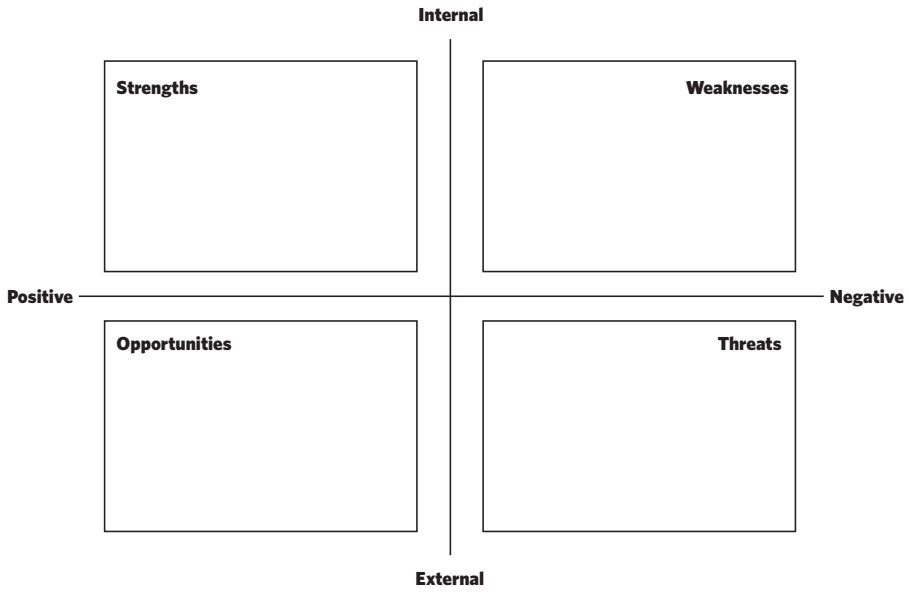
B. Make a SWOT analysis

Identify the Strengths, Weaknesses, Opportunities and Threats of your organization to achieve your organization's goal.

Steps to develop the SWOT analysis:

1. Define your organization's goal.
2. Assess the internal ***(Strengths)*** and external ***(Opportunities)*** factors that help to achieve your organization's goal.
3. Assess the internal ***(Weaknesses)*** and external ***(Threats)*** factors that hinder to achieve your organization's goal.

Organization's Goal:



Internal factors are the factors from inside your organization.
External factors are the factors from outside your organization.
Positive: What contributes to the achievement of the goal?
Negative: What hinders the achievement of the goal?

Session 3: TB and TB Control

3.1. Session Objectives:

Participants are able to present:

- Basic information on TB symptoms, prevention, diagnosis and cure
- The main TB problems and TB infrastructure in their own region

3.2 Basic information on TB and TB control

1. **What is TB?**
   TB is an infectious bacterial disease, most frequently lungs are affected (pulmonary TB), fatal if the disease is not treated

2. **What are the symptoms of lung TB?**
   More than 2 weeks productive cough
   - Weight loss
   - Night fever
   - Chest pain
   - Weakness
   - Loss of appetite.

3. **How does TB spread?**
   When a patient with lung TB coughs they infect other people through the droplets they spread in the air (aerosols) (Show a picture)

4. **How to prevent TB?**
   - Good ventilation in house
   - Cough hygiene (always)
   - Not spitting
   - Early diagnosis and treatment to avoid further spreading.

5. **How do you know you have TB?**
   Sputum test (2 samples, early morning and "on the spot")
   Visit a formally recognized and trained TB service provider

6. **How much does it cost to treat TB?**
   In public health services sputum tests are free of charge, as is treatment

7. **Is TB curable?**
   A person can be cured if they are treated in a timely manner and they take all their medicines as indicated by the healthcare provider. The earlier TB is diagnosed and treated, the better for the patient and their community.

8. **How long does the treatment take?**
   It takes 6 months, and the intake of the medicines has to be observed (DOTS) to make sure all drugs are taken. First 2 months every day (Intensive phase), 4 months (Continuation phase) according to country regime.

9. **What happens if a person cannot take treatment all these days?**
   They will not get cured, and may die, or the bacteria in their body will become resistant to the treatment. Treatment of resistant TB is very expensive, takes a much longer time and has lots of side effects. The drugs for (multi) drug resistant TB are also not available everywhere.

3.3 TB Problems and Infrastructure in your District/Region

Quiz

1. Where can you get TB treatment in your region?
2. Two main reasons for patient delay
3. How many people are treated successfully for TB in your region per year?
4. How many people die from TB in your region per year?
5. How many TB/HIV co-infected patients are there per year in your region?
6. How many CSO's are active in TB in your region?
7. Two main reasons for patient defaulter?
8. Two CSO activities in your region to prevent TB?
9. Two CSO activities in your region to enhance patient adherence?

Session 4: Stakeholders in TB Control

4.1. Objectives:

Participants are able to

- Identify roles, tasks and responsibilities of different stakeholders in TB control in their district / state
- Identify good and bad practices of collaboration among these stakeholders
- Define ways to improve collaboration for improved TB control

4.2 Assignment 1: Roles, tasks and responsibilities of stakeholders in TB control

Fill in the table "Tasks in TB control" to identify (1) the tasks different stakeholders have in TB control, (2) the quantity and (3) the quality of deliverables and (4) what could your CSO's role in this specific area. Present the table on a flip chart. (30 minutes)

Tasks in TB control

Tasks	1. Who is doing this	2. Are they doing it well: quantity	3. Are they doing it well: quality	4. What could be the CSO's role
Awareness raising for behavior change				
Identify and refer suspects				
Transport of sputum				
Sputum test				
Diagnostic of TB				
DOT and patient support				
Home visit and contact tracing				
Support patients groups				
Organize patient activist groups				
Organize Stop TB activities				

4.3 Key Messages

1. Different stakeholders have similar tasks
2. Tuberculosis Program sets standards for TB control
3. CSOs agree with TB program on possible tasks and deliverables
4. CSOs define their areas of interventions, depending on their vision, mission and resources
5. CSOs have an important and specific role to play in community involvement, patient support and empowerment

4.4 Assignment 2: Collaboration among stakeholders in TB control

Discuss in subgroups one of the following cases and share your results in plenary. (20 minutes)

1. Collaboration among CSOs

Two CSOs (A and B) , work in the same district and have both since 2006 DOTS providers for whom incentives are available. The incentives are paid till 2010 from the Global Fund budget. In 2011, fewer budgets are available for DOTS providers and the local TB coordinator has decided to give this budget to the other CSO B, whose chair is the brother in law of the District TB coordinator. CSO A is furious they accuse the TB program of a lack of transparency.

For discussion
1. Could this also happen in your region? How would you react?
2. What would be your advice to CSO A and CSO B?
3. How to prevent this conflict in future?

2. Collaboration between TB focal person and CSO

The CSO in district X is active in awareness raising and sputum collection. The TB focal person is not satisfied with their performance: the number of awareness raising activities in 2010 was much lower than the year before. The few sputum samples they collected are also of insufficient quality.

For discussion
1. Could this also happen in your district?
2. What could be reasons mediocre performance of the CSO?
3. How to improve the collaboration between the TB focal person and the CSO?

3. Collaboration between CSO and community volunteers

The CSO has trained in all their villages some volunteers to raise awareness in TB and give DOTS support where needed. In course of time gradually volunteers are not active anymore, not showing up also on meetings, as they feel they have too much work to do also with this unpaid voluntary work.

For discussion:
1. Do you recognize this situation?
2. What can you find as creative ways to solve this situation?

4. Collaboration between health facility and CSO

The community health workers are very active in the villages with awareness raising activities. The last 3 months more people come to the health facility with a simple 1 week cough, and want to be diagnosed for TB. This leads to an overburden of the laboratory and the responsible TB nurse. The TB nurse contacts the CSO, telling them not to send all these people with a one week cough to the clinic. The community health workers feel de-motivated and not taken seriously.

For discussion:
1. Could this also happen in your district?
2. How do you perceive the TB nurse's feedback?
3. How do you perceive the community health workers' reaction?
4. How to improve the collaboration between the health facility and the CSO?

5. Collaboration between health facility and CSO

Community health workers are very active with TB awareness raising activities in some villages. There is a substantial increase of people going to hospital with a two weeks old cough, asking for sputum diagnosis. These patients complain that they need to wait long hours and health workers behave rude, sometimes even don't take time for a proper intake.

For discussion:
1. Could this also happen in your district?
2. How do you perceive the health workers behavior?
3. What do you advise the CSO to do?

4.5 Key Messages for Fruitful Collaboration

1. Keep in mind that you have a common goal: Fight against TB (don't fight with each other)
2. Inform each other about activities and results
3. Have regular meetings
4. Contact each other when there are problems to discuss and look for solutions
5. Build good relationships
6. Respect the position, responsibilities and competencies of the others

4.6 Assignment 3: Actions to improve the collaboration

Work in your CSO group and define some actions to improve collaboration with different stakeholders. NTP representatives define some actions to improve collaboration with the CSOs. (15 minutes)

Session 5: Stigma, Human and Patient Rights'

5.1 Objectives:

Participants are able to:

- Identify different forms and causes of stigma for TB or TB/HIV
- Explain how stigma affects health seeking behavior and adherence to treatment
- Identify how stigma violates human rights
- Present ways to reduce stigma in the community and their role as a CSO.

5.2 Assignment 1: Exploring stigma in different contexts

Look at one of the identified contexts: what stigma against TB do you observe?
What are the attitudes, feelings and behavior against people that have TB?

5.3 Cases of Stigma

1. Joshua works in a private company and was recently diagnosed with TB. He was put on two months leave and when he reported back for work, found he was being transferred to a new town. On arrival at the new place he was told there was no vacancy for him. He went back to the head office to find out what was happening and was told to wait at home for a while. After a month, he received a letter terminating his contract. The letter argued that because of his poor health he would be unable to contribute effectively to his work.
2. Robert is a married man with three children. He and his family were chased out of his house when his landlord discovered that he had TB. The landlord said he didn't want Robert to infect other people and that it would be bad for his business.
3. Selina is a young woman who is living with her grandmother. She was diagnosed with TB a few months ago and has been responding well to treatment. Recently she met a young man whom she really likes and hopes to marry one day. However, her grandmother has told her that she cannot be in a relationship – she must wait until her TB treatment is finished and she is sure that she is well.
4. Natalie has been on TB treatment for two weeks and has not been responding well. She is very sick. Her family calls a meeting and decides that she should stop taking the drugs and go to her grandmother's house in the village where she can rest and recover.
5. Kenneth has had TB for the last three months and is responding well to treatment. He stays with his family and while he is there, the family starts planning the wedding of his youngest sister. Kenneth asks to help with the wedding arrangements, but his father tells him, "People like you don't need to be involved in these things".

5.4 Assignment 2: The Parliament

Statement "TB patients' human rights are violated"

5.5 Examples of Human & Patients' Rights for TB patients

Right to Health Care: Health staff may ignore other diseases which a patient may have and focus solely on HIV or TB. Family may refuse to finance medical costs. Family may stop the patient from being treated at the clinic and take the patient to a traditional doctor.

Right to Information: TB patients not given enough/correct information about TB, treatment, how TB is transmitted. When you go to the clinic the nurse doesn't take time to really explain everything, she/he just wants to see you leave.

Right to Shelter/Accommodation: Sometimes you are chased from your house or taken back to the village. May be put in poor and unhygienic accommodation. If the landlord discovers you have TB, he may chase you away.

Right to Work: Fired for having TB; Forced into 'early retirement' on 'medical grounds'. Told you are a 'threat' to your workmates.

Right to be Loved: Separated from family, children and partners. Forced to terminate a relationship because your spouse's family chases you away.

See also the Patients' Charter.

5.6 Patients' Charter

THE PATIENTS' CHARTER FOR TUBERCULOSIS CARE (Edition 2010)

The Patients' Charter (PCTC) outlines the rights and responsibilities of people with tuberculosis. It empowers people with the disease and their communities through this knowledge. Initiated and developed by TB patients from around the world, the Charter makes the relationship with health care providers a mutually beneficial one.

The Charter sets out the ways in which patients, the community, health providers, both private and public, and governments can work as partners in a positive and open relationship with a view to improving tuberculosis care and enhancing the effectiveness of the health care process. It allows for all parties to be held more accountable to each other, fostering mutual interaction and a 'positive partnership'. Developed in tandem with the International Standards for Tuberculosis Care(1) to promote a 'patient-centered' approach, the Charter bears in mind the principles on health and human rights of the United Nations, UNESCO, WHO, Council of Europe, as well as other local and national charters and conventions(2).

The Patients' Charter practices the principle of Greater Involvement of People with TB or GIPT(3). This affirms that the empowerment of people with the disease is the catalyst for effective collaboration with health providers and authorities, and is essential to victory in the fight to stop TB. Accordingly, the PCTC is included as a key element of the WHO STOP TB Strategy, and was launched by Dr. Lee, DG of WHO on World TB Day 2006. The Patients' Charter, the first global 'patient-powered' standard for care, is a cooperative tool, forged from common cause, for the entire TB Community.

PATIENTS' RIGHTS

Care

- The right to free and equitable access to tuberculosis care, from diagnosis through treatment completion, regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture or having another illness.
- The right to receive medical advice and treatment which fully meets the new International Standards for Tuberculosis Care, centering on patient needs, including those with X/MDR-TB or TB-HIV co-infections, and preventative treatment for young children and others considered to be at high risk.
- The right to benefit from proactive health sector community outreach, education and prevention campaigns as part of comprehensive care programs.

Dignity

- The right to be treated with respect and dignity, including the delivery of services without stigma, prejudice or discrimination by health providers and authorities.
- The right to quality health care in a dignified environment, with social support from family, community and national programs.

Information

- The right to information about what health care services are available for tuberculosis, and what responsibilities, engagements, and direct or indirect costs, are involved.
- The right to receive a timely, concise and clear description of the medical condition, with diagnosis, prognosis (an opinion of the likely future course of the illness), and treatment proposed, with communication of common risks and appropriate alternatives.
- The right to know the names and dosages of any medication or intervention to be prescribed, its normal actions and potential side-effects, and its possible impact on other conditions or treatments.
- The right of access to the medical record concerning the patient's condition and treatment, and a copy if requested by the patient or a person authorized by the patient.
- The right to meet, share experiences with peers and other patients, and to voluntary counseling at any time from diagnosis through treatment completion.

Choice

- The right to a second medical opinion, with access to previous medical records.
- The right to refuse surgical interventions if chemotherapy is at all possible, and to be informed of the likely medical and statutory consequences.
- The right to choose whether or not to take part in medical research programs without compromising the quality of care.

Confidence

- The right to have personal privacy, dignity, religious beliefs and culture respected.
- The right to have information relating to the medical condition kept confidential, and released to other authorities contingent upon the patient's consent.
- The right to health care services in facilities that practice effective infection control.

Justice

- The right to make a complaint through channels provided for this purpose by the health authority, and to have any complaint dealt with promptly and fairly.
- The right to appeal to a higher authority if the above is not respected, and to be informed in writing of the outcome.
- The right to vote in open elections for patient representatives on health related bodies, and to develop accountable systems of representation to defend the rights of patients.

Organization

- The right to join, or to establish, organizations of people with or affected by TB, and to seek support for the development of these clubs, peer support groups, and community based associations through the health providers, authorities, and civil society partners.
- The right to participate as 'stakeholders' in the development, implementation, monitoring and evaluation of policies and programs for TB Care with local, national and international health authorities.

Security

- The right to job security after diagnosis and /or appropriate rehabilitation upon 'cure'.
- The right to nutritional security or food supplements that are necessary to meet treatment regime requirements.
- The right to anti-tuberculosis drugs and diagnostics that are Quality Assured by a stringent authority or WHO pre-qualification.

PATIENTS' RESPONSIBILITIES

Share Information

- The responsibility to provide the health care giver as much information as possible about present health, past illnesses, any allergies and any other relevant details.
- The responsibility to provide information to the health provider about contacts with immediate family, friends and others who may be vulnerable to tuberculosis or may have been infected by contact.
- The responsibility to inform family and friends, and to share lessons learned of TB.

Follow Treatment

- The responsibility to follow the prescribed and agreed treatment plan, and to conscientiously comply with the instructions given to protect the patient's and other's health
- The responsibility to inform the health provider of any difficulties or problems with adhering to treatment, or if any part of the treatment is not clearly understood.

Contribute to Community Health

- The responsibility to contribute to community well being by encouraging others to seek medical advice if they exhibit the symptoms of tuberculosis.
- The responsibility to show consideration for the rights of other patients and health care providers, understanding that this is the dignified basis and respectful foundation of the TB Community.
- The responsibility to help family, friends and neighbors adhere to treatment, from start to completion with cure.

Show Solidarity

- The moral responsibility of showing solidarity with other patients, marching together towards cure.
- The moral responsibility to share knowledge gained during treatment, and to pass this expertise to others in the community, making empowerment contagious.
- The moral responsibility to join in efforts to make the community TB Free.

1. International Standards for Tuberculosis Care:
http://www.who.int/tb/publications/2006/istc/en/index.html
2. United Nations CESCR General Comment 14 on the right to health:
http://www.unhchr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En
- WHO Ottawa Charter on health promotion:
www.who.int/healthpromotion/conferences/previous/ottawa/en
- The Council of Europe Convention for the Protection of Human Rights and Dignity/ biology and medicine:
http://conventions.coe.int/treaty/EN/Treaties/Html/164.htm
- UNESCO Universal Draft Declaration on Bioethics and Human Rights:
http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html
3. Greater Involvement of People with Tuberculosis (GIPT):
http://www.worldcarecouncil.org/content/greater-involvement-people-tb-gipt

Help turn these words into practice, and your rights into realities. Join the mobilization in your country for the implementation of the Patients' Charter for Tuberculosis Care.
In common cause, with mutual respect, together we can raise the standards of care for people with TB and TB-HIV co-infection.

Learn more / downloads at http://www.patientscharter.org

This Edition 2010 of the Patients' Charter has been made possible by the generous support of the American people through the United States Agency for International Development (USAID), TB CTA, and the World Care Council.

USAID FROM THE AMERICAN PEOPLE
WORLD CARE COUNCIL
TB CTA The Tuberculosis Coalition for Technical Assistance

5.7 Assignment 3: Silent wall discussion to address stigma and role of CSOs

1. What actions are needed to address stigma against TB?
2. What can CSOs do to address stigma, human rights & patient rights of TB patients?

WORLD ECONOMIC FORUM
COMMITTED TO IMPROVING THE STATE OF THE WORLD

TB: Why you should not discriminate*

** Adapted from ICN Document: TB/MDR TB Related Stigma and Discrimination*

Impact of Stigma and Discrimination

Tuberculosis is an infectious disease caused by bacteria that any person can get. It is not a hereditary disease or a curse of God. It can be completely cured by taking regular and complete treatment. Stigma and discrimination against people diseased with TB can occur in many settings at the workplace, health care facilities, or within the community. Its manifestation can be as dramatic as physical violence or as subtle as avoidance. However, it is totally unnecessary and primarily based on myths.
Stigma is as old as history. Stigma and discrimination against people infected with TB can occur in many settings at the workplace, healthcare facilities, or within the community. Its manifestation can be as dramatic as physical violence or as subtle as avoidance. However, it is totally unnecessary and primarily based on myths. Beyond the economic consequences, stigma and discrimination against people with TB have a devastating social and psychological impact. Such attitudes obstruct health care providers in delivering effective treatment. Stigma often prevents people from seeking health care attention, which constitutes a direct public health threat to the community. Even when patients attend treatment, social disapproval of their family or community members decreases compliance with treatment. Proper adherence, however, is critical to avoid the development of multi-drug resistant TB (MDR-TB). Social isolation, experienced rejection, shame and blame due to TB diagnosis can lead to psychosomatic stress, loneliness and feelings of hopelessness.

Some of the causes of stigma & discrimination include:

- Lack of knowledge about TB transmission, diagnosis and treatment.
- Association with conditions already stigmatized, particularly HIV/AIDS, poverty, malnutrition, migration and poor hygienic living conditions.
- People with TB are often seen as being responsible for becoming infected.
- People living with TB are seen as guilty of infecting others.
- Lack of protective equipment for health care workers.
- Lack of access to treatment.

TB related stigma and discrimination can be minimized!

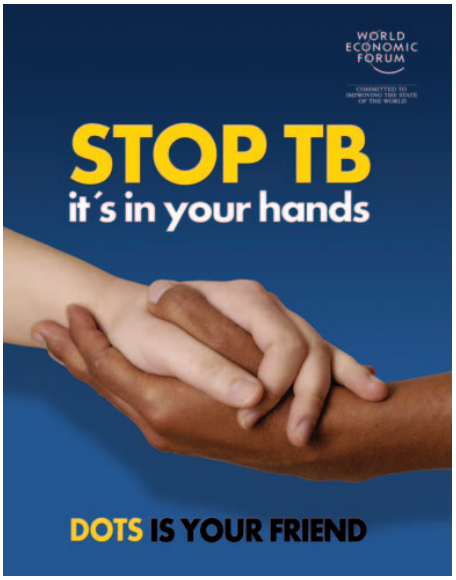
It is important that employees and healthcare professionals understand the determinants and dynamics of stigma to ensure that they prevent the violation of human rights, that patients seek timely advice and achieve good treatment adherence. It is suggested that company management implement the following strategies to minimize TB related stigma and discrimination at the workplace:

- Provide a supportive work environment, where people can disclose their TB status without the threat of being stigmatized and risk losing their jobs. Have in place a policy that addresses this so that workers don't lose their jobs because of being diagnosed as TB; rather such TB patients are provided proper care and access to DOTS services.
- Influence people's attitudes through awareness about TB, to provide up to date information on TB epidemiology, diagnosis, transmission, treatment and address TB related stigma and discrimination. Increasing factual knowledge should be followed by experiential learning, which helps employees reflect their own attitudes about TB and understand individuals affected by TB stigma and discrimination.
- Involve those with personal experience with TB and set up "Support Groups". Such groups can encourage the exchange of experiences related to TB and address issues concerning social and workplace support.
- Initiate workplace campaigns to change attitudes. The aim of these campaigns is to provide accurate, up-to date information on TB ('TB is curable').
- Develop sustainability of TB anti-stigma campaigns through partnerships with private and public national and international companies.
- Respect confidentiality. Risks of disclosure might include negative responses, such as rejection, isolation and loss of employment. This can result in poor treatment adherence and/or the spread of TB to other employees.
- Link with existing HIV/AIDS anti-stigma workplace initiatives.
- Ensure occupational safety for health care staff and appropriate working conditions for all, e.g. ensuring good ventilation of premises and/ or applying air filtration.

TB anti-stigma interventions should be in place in every company.

TB: Why you should not discriminate

The Myths	The Truth
• TB is a life-threatening disease	• TB can be cured by taking a course of medicine
• You can become infected by TB by touching someone who has it or being with someone who has it for a few minutes	• TB is transmitted only by prolonged close contact with coughing infectious patients
• If someone has TB they are infectious	• TB patients who have taken their treatment for 2 weeks and are still taking treatment are usually not infectious
• Only the poor and malnourished get TB	• Anyone can get TB rich or poor and become unwilling host to bacteria
• Once you have TB you are doomed and cannot get treated	• TB treatment is freely available at government clinics, and correct treatment cures the vast majority of cases



Session 6: Health Education

6.1 Objectives:

Participants are able to:
- Identify their CSO's priority target groups for TB health education
- Present key lessons about health education for behavior change
- Develop, implement and evaluate a health education session for different target groups

6.2 Assignment 1: Health education for TB control

Discuss in buzz groups (10 minutes):
1. What is the purpose of health education for TB control?
2. Who are your priority target groups?
3. What are the key messages?

Write your answers on the different flip charts, only add that what is not on the flip chart yet.

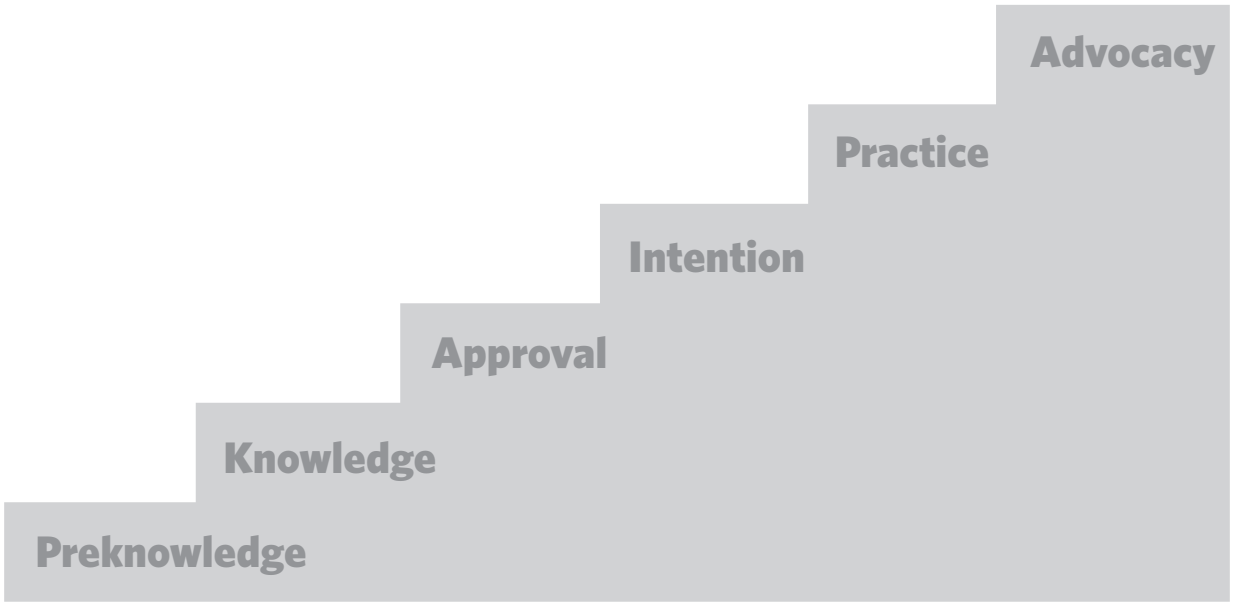
6.3 Assignment 2: Personal Example of Behavior Change

Share a personal example of unhealthy behavior you wanted to change. How did you approach this? Were you successful? What made you change or not change?

6.4 Behaviour Change

Behavior change is a process. People usually move through several intermediate steps before changing their behavior. These steps are:

Pre-knowledgeable - Is unaware of the problem or of their personal risk.
Knowledgeable - Is aware of the problem and knowledgeable about desired behaviors.
Approving - Is in favor of the desired behaviors.
Intending - Intends to personally take the desired actions.
Practicing - Practices the desired behaviors.
Advocating - Practices the desired behaviors and advocates them to others.



Behaviour-change communication aims to change knowledge, attitudes and practices among various groups of people. It frequently informs the public of the services that exist for diagnosis and treatment and relays a series of messages about the disease – such as "seek treatment if you have a cough for more than two weeks", "TB hurts your lungs" or "TB is curable". There is a simple rule with regard to communication: do it early, do it often and don't stop until the job is finished.

Effective behaviour-change communication and messages need to convey more than just the medical facts as, on their own, these facts do not necessarily motivate people to visit a TB clinic or complete their treatment. The messages should explore the reasons why people do or do not take action on the information they receive, then focus on changing the actual behaviour by addressing the causes identified – for example social norms or personal attitudes.

Behaviour-change communication creates an environment through which affected communities can discuss debate, organize and communicate their own perspectives on TB. It aims to change behaviour – such as persuading people with symptoms to seek treatment – and to foster social change, supporting processes in the community or elsewhere to spark debate that may shift social moves and/or eliminate barriers to new behaviour. People at different stages constitute distinct audiences. Thus, they usually need different messages and sometimes different approaches, whether through interpersonal channels, community channels or mass media.

6.5 Assignment 3: Develop and implement a health education session

A. Prepare a 10 minute health education session for one of the following target groups:

1. The members of the female farmers' group in the district
2. DOTS providers in the district
3. Journalists in the province
4. Secondary School students

To Prepare

1. Describe the target group:
   - Why is this health education session relevant for them?
   - What do you expect them to know about TB?
   - What is their attitude towards TB?

2. Define the purpose of the health education session

3. Define the key content of the session

4. Define the methodology that you will use during the session (e.g. talk, powerpoint presentation, ask questions, do a quiz etc.)

5. Which IEC materials will be used?

B. Implement the 10 minute health education session

C. Ask the audience for feedback

Session 7: Social Mobilization

7.1 Objectives:

Participants are able to:

- Define concept and purpose of social mobilization
- Present their CSO's social mobilization approach, the results and challenges faced
- Identify new allies to address TB challenges in their region

7.2 Assignment 1: Community mobilization approaches

Discuss the topic that is on the flip chart, and write your inputs down. Give the flip chart to the next table when indicated by the trainers. (15 minutes)

Topics:

- Purpose of Community Mobilization
- Which social groups are active in your communities?
- How the CSOs mobilize the communities
- CSO's results with Community Mobilization
- What are the challenges you meet in community mobilization?

7.3 Defining Social Mobilization

Social mobilization is a process of engaging all sectors of the population in a community-wide effort to address a health, social, or environmental issues. It brings together policy makers and opinion leaders, local, state, and national governments, professional groups, religious groups, businesses, and individual community members.

Social mobilization empowers individuals and groups to take some kind of action to facilitate change. Part of the process includes mobilizing necessary resources, disseminating information, generating support, and fostering cooperation across public and private sectors in the community. Anyone can initiate a community mobilization effort - the TB staff of local or district health departments, Community-based organizations (CBOs), or concerned physicians and other health professionals. All it takes is a person or a group to start the process and bring others into it.

7.4 Assignment 2: Identifying New Allies

	What is the problem or challenge?	Which change is needed?	What is your target?	Who can be your social mobilizer (agent of change)?	How to get the new allies on board?
1.	High defaulter rate among at risk slum dwellers	Special attention through home visits by treatment supporters, inclusion in state special benefit scheme	Provide social treatment supporters and guide patients to Ministry of Welfare procedures	Church members, Women's groups	
2.					
3.					

Session 8: Advocacy for TB Control

8.1 Objectives:

Participants are able to:
- Present the concept of advocacy and its relevance for their CSO
- Identify

8.2 Defining Advocacy

Advocacy has many definitions, but one is: "Advocacy is a process to bring about change in the policies. Laws and practices of influential individuals, groups and institutions" It is a process of change, a series of activities linked to a defined goal. It can take many forms, written, spoken, sung or acted and it can vary also in time (few minutes to several years). Example: CSOs holding a press conference or jointly signing an open letter; meeting with country's Minister of Health, drama about patient rights performed for key decision makers, etc. Advocacy is a key activity for civil society as influencer and watchdog, ensuring that governments and stakeholders keep their word.

8.3 Assignment: Identifying advocacy points and decision makers

Discuss in buzz groups the following questions and share them in plenary

- Identify one of the TB challenges defined in the previous session (Social Mobilization).
- Define the advocacy point
- Define the decision makers you need to address your advocacy to.

8.4 Advocacy Strategy

An effective advocacy strategy has the following components:
1. Clear and relevant advocacy points addressing priority challenges
2. Target groups that can address these advocacy points
3. Long term relationships building
4. Interactive communication

8.4.1 Clear and Relevant Advocacy Points

To define the advocacy points, you need to identify first the major TB challenges. Herewith some examples:

Challenge 1:
Laboratories for sputum microscopy are only in bigger health centers due to lack of lab personnel at lower levels, and limit access to early diagnostics.

Advocacy Point:
Create laboratory positions at decentralized labs in order to do TB microscopy.

Challenge 2:
Migrant and oftentimes illegal workers are not having access to (TB) services as they do not have the identity card which entitles them to public services.

Advocacy Point:
Facilitate access to free diagnostic and TB care for this vulnerable group.

8.4.2 Target groups that can address these advocacy points

Identify the individuals and/or organizations that can make change the advocacy points. These may be people/ organizations that have control over financial or human resources, political decision making etc.

8.4.3 Long term relationship building

Advocacy means also investing in long term relationships, to build trust and commitment so that organizations/individuals are willing to use their power to facilitate change.

8.4.4 Interactive Communication

1. Find out who the person is: interests, what they are committed to, history..
2. Relate to them as a human being, not as an institution
3. Find common ground
4. Acknowledge them
5. Ask what they need to help move the cause forward, Offer to help
6. Be polite
7. Have clear, concise, positive messages
8. Inspire them with your passion (not your anger)
9. Follow up on agreed actions (including your own)
10. Keep your promises (as a model for them)
11. Generate genuine partnerships
12. Work with patient advocates.

Advocacy partnership: http://www.advocacypartnership.org

Session 9: Funding in TB control

9.1 Objectives:

Participants are able to

- Give an overview of funding possibilities for CSO activities in TB control
- Present the Global Fund mechanism
- Identify their organization's opportunities to participate in Global Fund proposal writing

9.2 Assignment 1: Current and future funding sources and funding challenges

Make an overview (on flip chart) of your CSO's current funding sources and your ambitions for the coming 5 years. Present the overview in plenary.

Name of the CSO:

1. Current situation

Funding sources

Funding challenges met

2. The coming 5 years

Funding ambitions (Do you want to grow? How much?)

Funding opportunities for the coming 5 years (which funding sources could you access?)

Funding challenges expected

9.3 Assignment 2: Prepare the interview

Identify all questions related to CSO's funding for TB control, you would like to ask the panel.

Session 10: Annual Action Plan

10.1 Objectives:

Participants are able to:

- Develop a draft annual action plan for their organization
- Identify their role in the finalization and implementation of this plan
- Identify the organization's support needed for the finalization and implementation of this plan
- Use the monitoring and reporting tool

10.2 Assignment to develop an annual action plan

Develop a draft action plan for your CSO for the coming year. The action plan needs to include (1) key activities in TB control and (2) developing the organization's capacity so that it will be able to contribute to TB control in your district/state. (60 minutes)

This draft action plan needs to be discussed and developed further within your organization.
Present the draft action plan to one of the other organizations (10 minutes) and ask for feedback (20 minutes).

1. Define your CSO's ambitions for the coming year

1.1 To build its organizational capacity
In which fields the organization's capacity needs to be built? Go back to the SWOT analysis and the stakeholders' analysis to identify your organization's weaknesses and to your logbook to use the suggestions developed during training course

1.2 To implement TB control activities
What tasks and responsibilities your organization will take up in the field of TB control? Make use of the ideas in your logbook.

2. Develop an action plan (A) to build the organization's capacity

Identify the activities needed to build the organization's capacity, the target group, when these activities will take place, who is responsible for this activity, if funding is needed and available.

Activity	Target group	When this activity takes place	Who is responsible for this activity	Funding needed yes/no	Funding available yes/no

3. Develop an action plan (B) to implement TB control activities

Identify the TB control activities to be implemented in the coming year, when these activities take place, who will be involved in the implementation of these activities, who is responsible for this activity, if funding is needed and if funding is available

Activity	Target group	When this activity takes place	Who is responsible for this activity	Funding needed yes/no	Funding available yes/no

4. Finalize the action plan

4.1. How and when do you plan to finalize this action plan (A+ B) ?
4.2. What is your role in the finalization of this action plan?
4.3. What support (from the mentoring organization and others) is needed in the development and implementation of this action plan?

10.3 Monitoring and reporting implementation

1. The organization's monitoring system

Decide within your organization how to monitor the implementation of your annual action plan:

a. Who is responsible for this?
b. Which tool to use?
c. What is the monitoring frequency?
d. What to do with the monitoring information?

2. Reporting

Every mentee CSO makes a quarterly mentoring progress report and sends this to the country project coordinator and the mentoring organization on the dates given.

Mentee Organization's Report

Send to the Country Project Coordinator and the mentoring organization (Indicate the dates):

Name of the mentee organization:	
Quarter:	

A. Activities and Progress

TB control activities carried out	Please list the activities here:
Progress made in your organizational performance	Please list your progress here:
What were your challenges?	Please list your challenges here:

B. Action Plan

Have you implemented your action plan A in this quarter?	Which activities of your action plan A did you implement in this quarter?
	Which activities of your action plan A did you not implement this quarter?
	Which activities did you implement that are not in your action plan?
Have you implemented your action plan B in this quarter?	Which activities of your action plan B did you implement in this quarter?
	Which activities of your action plan B did you not implement this quarter?
	Which activities did you implement that are not in your action plan?

What were the most important lessons that you learned?	

Session 11: Course Evaluation

Participants' Feedback Sheet

This feedback sheet has 2 components:

A: to be filled in by all participants individually
B: To be filled in per CSO

A: Individual feedback
Please rate (for every session) what you thought of the content and of the methodology. Write the numbers in the table behind the name of the session.

Excellent	Good	All right	In need of improvement	Poor
5	4	3	2	1

Title of Session	The content was...	The methodology was...
1. Introduction		
2. Presenting your organization		
3. TB and TB control		
4. TB, stigma and human rights		
5. Stakeholders in TB control		
6. TB health education		
7. Social Mobilization for TB control		
8. Advocacy for TB control		
9. Funding for TB control		
10. Action Planning		

Overall, did you learn in these four days what you needed to learn? (Please explain)

Which topics would you have liked to cover in the training that were not covered?

Which topics should have received more time?

Which topics could have been covered in less time?

Is the training material comprehensive enough? What should be added or removed?

Can the clarity of the training materials be improved? If yes, how?

To what extent have you achieved your personal objectives for this training?

Fully	5	4	3	2	1	Not at all

What is your overall rating of this training program?

Excellent	5	4	3	2	1	Poor

Make any comments on your ratings that you feel will be of help to the designers of this training program.

B: To fill in per organization

Indicate with an X what type of organization you are:

Mentoring Organization	
Mentee Organization	

Please circle the score that most closely represents your views.

1. To what extent have you developed your knowledge and skills to contribute to TB control activities?

A lot	5	4	3	2	1	Not at all

2. To what extent have you developed your knowledge and skills to build the capacity of your organization or to build the capacity of the mentee organizations?

A lot	5	4	3	2	1	Not at all

3. To what extent have you developed your knowledge about the stakeholders in TB control?

A lot	5	4	3	2	1	Not at all

4. To what extent would you recommend others with similar needs to your own to attend this training?

Could you explain why?