Global Coalition of TB Activists

spiritia

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

29 April – 2 May 2019
Jakarta, Indonesia

Summary

Twenty-one community members from key affected populations participated in the *Transforming the TB Response – Capacity Building of Communities to be Change-Agents Training* held in Jakarta, Indonesia from 29 April – 2 May, 2019.

The workshop was conducted by GCTA in collaboration with Spiritia. The objective of the workshop was

- To train and empower key affected populations to be Change-Agents and assist National TB Control Program in finding missing cases

- To bring together community members from key populations to discuss issues at the global, regional and country-level that are relevant to enable community-led TB response

- To mentor and provide technical support to community members to enhance their knowledge on latest development on TB treatment regime; access issues, gaps and challenges

The main expected outcome of the workshop was training twenty-one Change-Agents who will advocate for a community-led TB response. GCTA will provide technical support and assistance to the Change-Agents as per their requirement and need.

Transforming the TB Response to END TB

According to WHO, in 2017, TB claimed 1.6 million lives including 0.3 million among people living with HIV even after being a completely curable disease. In the same year, 10 million people fell ill due to TB out to which 3.6 million people were either undiagnosed or untreated. Part of this is due to the lack of meaningful engagement with the community and community empowerment, followed by under-diagnosis, under-reporting and, inadequate access to health services due to stigma and other barriers. Taking from SDG UHC and UNHLM agenda to eliminate TB, it is crucial to empower communities and ensure meaningful community engagement to end TB. However, to date, the response has been largely medical and those affected by TB and their families have had little or no part to play in the fight against TB. Their potential role as powerful advocates, with the ability to improve public understanding of the disease, support those affected, and to destigmatize the disease has remained largely untapped.

GCTA developed the training modules for building capacity of affected community to be "Change-Agents" who can assist the National TB Programs at country level for finding the missing people affected by TB and ensure timely diagnosis, treatment and care for all those in need.

Indonesia with the third highest incidence of TB in the world, after India and China was the site for the first training conducted by GCTA using the aforementioned modules.

Module Components

Treatment Literacy

Advocacy

Communication
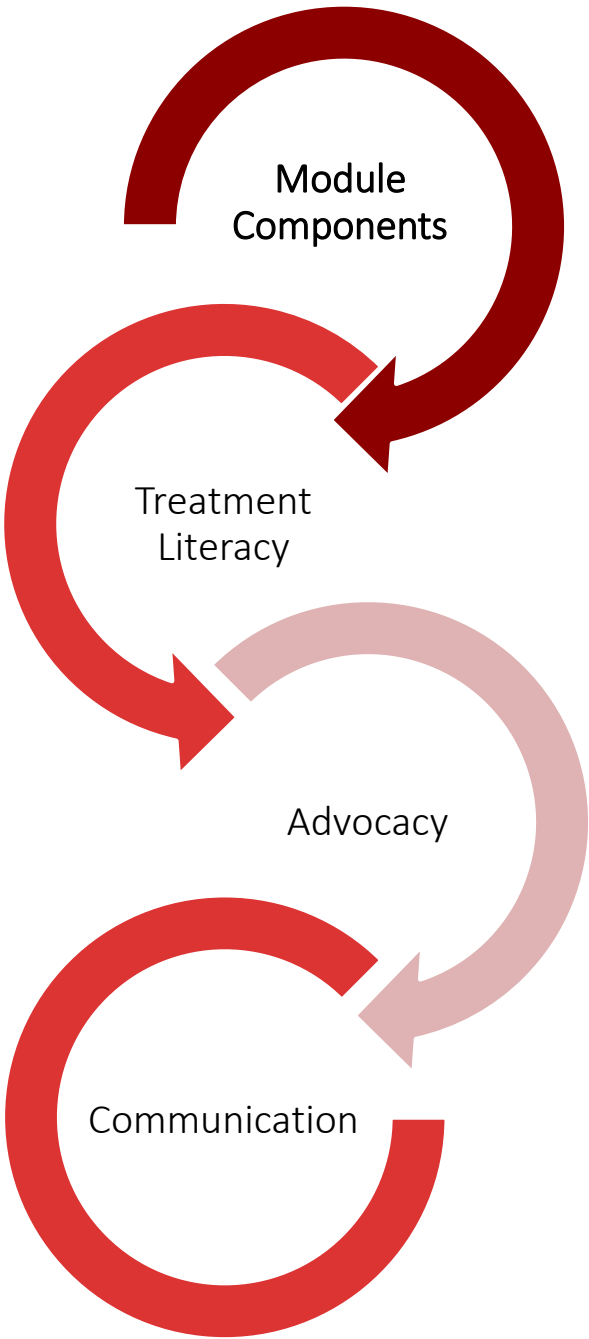
Indonesia TB Burden	
Population – 264,000,000	
TB Incidence	HIV Positive TB Incidence
842,000	36,000

Training Objectives

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- To mentor and provide technical support to community members to enhance their knowledge on latest development on TB treatment regime; access issues, gaps and challenges
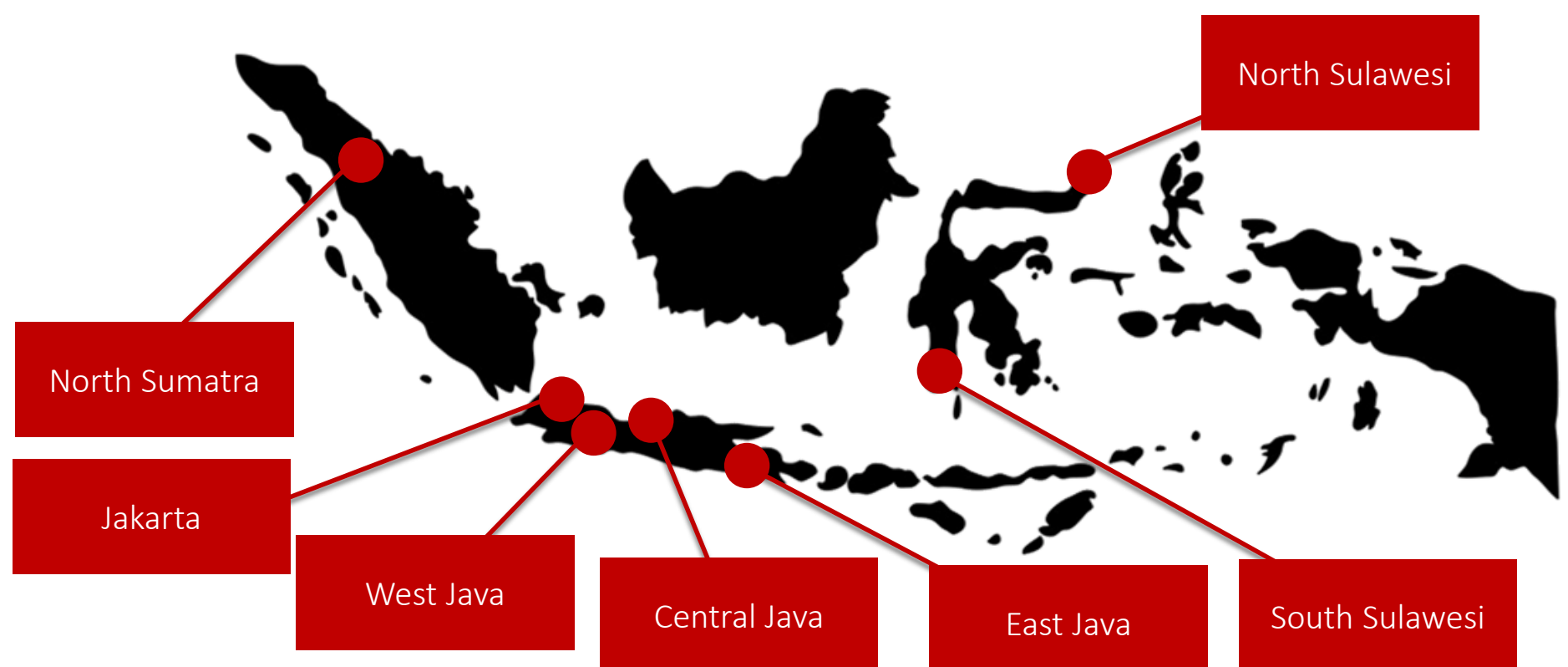
Our Partner: Spiritia

Spiritia is a civil society organization based at Jakarta, Indonesia. Spiritia works with and for people living with HIV/AIDS since 1995. They are also part of ACT-AP (Asia-pacific Coalition of TB Activists),and the regional principal recipient of The Global Fund grant in Indonesia for TB and HIV.

Spiritia's position and work in the country gives them an unique insights into the civil society in Indonesia and hence they were able to select the right participants for the training.

The participants were representatives of key affected populations and TB survivors from underserved areas. Special attention was given to include individuals co-infected with TB and HIV.

Fig 1: Participant Profile

North Sulawesi

North Sumatra

Jakarta

West Java

Central Java

East Java

South Sulawesi

Supporters of Community Activism in TB

The training commenced with the inaugural plenary and representation from partner organizations like Centre for Disease Control, KNCV and Spiritia and community representative from CCM Technical Working Group for TB also joined us. Univocally all partners congratulated GCTA on taking an important stride in community empowerment through the training.

Opening the inaugural plenary GCTA Board Member Elvi Siahaan said, "Indonesia with 17,000 islands is a big country and we have the third place in TB prevalence globally. Unfortunately, our government has limited resources and cannot reach all areas. They need our support. With GCTA's training modules we will be able to equip the community members to be Change-Agents and support the National TB Program to find the missing cases and ensure that Indonesia can eliminate TB". A. Rahmat Hidayat, Planning, Monitoring & Evaluation Manager, Spiritia added to this by stating, "As people who work closely with the communities, you (the participants) hold the power to be able to eliminate TB from Indonesia and ensure everyone has access to appropriate care and treatment for TB." Wiendra Waworuntu from CDC, in her address, attributed trainings like these to be one of the key factors for building the highest degree of public health in a country and create a high quality of life for all. Erman Varella from KNCV talked about the importance of involving communities and building their capacity. Blessina Kuma, GCTA, called attention to the number of lives lost every day to a completely curable disease like TB and urged one and all present to work together to make Indonesia TB Free!

Day 1: Setting the Tone

The aim of day was to break-the-ice between the facilitators and the participants to create a collaborative and conducive environment for learning and growing together. Blessina Kumar, GCTA opened the day with an icebreaker exercise. This was followed by a free-flowing expectation sharing session where all the participants were given a chance to vocalize their expectations from the training. The group also set ground rules for the proceedings of the training and rendered their informed consent to be photographed as a part of the training. The day came to a close with the participants taking the pre-test to the training.

Fig 2: Participant Expectations

To know more about TB

What can be done to end TB

Learn how I can help my friends who are affected by TB

To learn new things about TB and the next steps in TB response

To learn advocacy

To learn how to reduce stigma

Empower myself to educate my HIV+ friends to protect themselves from TB

Empower myself to play a role in reducing the TB burden in Indonesia

Educate myself to educate my transgender friends about TB

To know more about MDR-TB

To know more about childhood TB

To network with fellow activists

To learn about multi-sectoral engagement

To be agents of change to end TB

To become a team to end TB

Day 2: Challenges and Priorities for People Affected by TB

The aim of the day was to bring all the participants on the same page in terms of their knowledge and understanding about TB. The day was designed to approach TB through a multi-faceted lens. The sessions of the day concentrated on facts related to TB diagnostics, treatment, care and prevention (PART 1) along with providing a space for exploring the lived-experience of TB (PART 2) and how stigma affects and interweaves itself into these two facets of the disease (PART 3).

1. PART 1 – Basics on TB, Treatment and HIV/TB co-infection and TB at a Glance: These sessions sought to look at the factual base of the TB disease. Nurjannah Sulaiman from NTP Indonesia presented the Indonesia TB landscape and Blessina Kumar, GCTA presented data on global TB landscape. This was followed by a session on TB diagnostics, treatment, latent TB infection, childhood TB and TB prevention. It is noteworthy that sections on TB diagnostics and childhood TB were not a part of the original module. However, post hearing the expectations from the participants, GCTA, adjusted the agenda and added these sections to effectively incorporate and address all the participants' expectations.

Every person has the right to access appropriate treatment and care. The government is committed to ensure that all TB patients have access to treatment. Public and private partnership needs to aid access to care and treatment to ensure that Indonesia can eliminate TB by 2030 and eradicate TB 2050.

- Nurjannah Sulaiman

The idea of DOTS is based on an idea of mistrust in the communities. We do not trust the affected communities to take their medication?

- Blessina Kumar

I was offended that the facilitator called DOTS useless.

- Anonymous
(*Comment rendered as a part of a feedback form*)

2. PART 2 – TB & Me – Story Sharing Session: This session gave space to TB survivors to share their journey without instruction or direction. In the context of TB, where so often the human side of the disease and the lived-experience of the survivors is neither known nor given attention to, this space provided a unique and welcoming opportunity for people to talk openly about their very personal experiences.

> I was stigmatized at my work place and they fired me after they came to know that I have TB.
> - Chairul

> After I lost my mother to TB my step-mother discriminated against me due to my diagnosis.
> - Tasya

> I had burning sensations all over my body when I was on medication. It got so bad that I wanted to kill myself.
> -Denny

3. PART 3 – Care Cascade: This participatory session invited the participants to identify the barriers to accessing care and treatment. In this exercise, the participants analyzed and grouped the problems under challenges faced in both health and community settings. The TB response often centers on the health system challenges in isolation and leaves out the societal barriers that are equally disruptive.

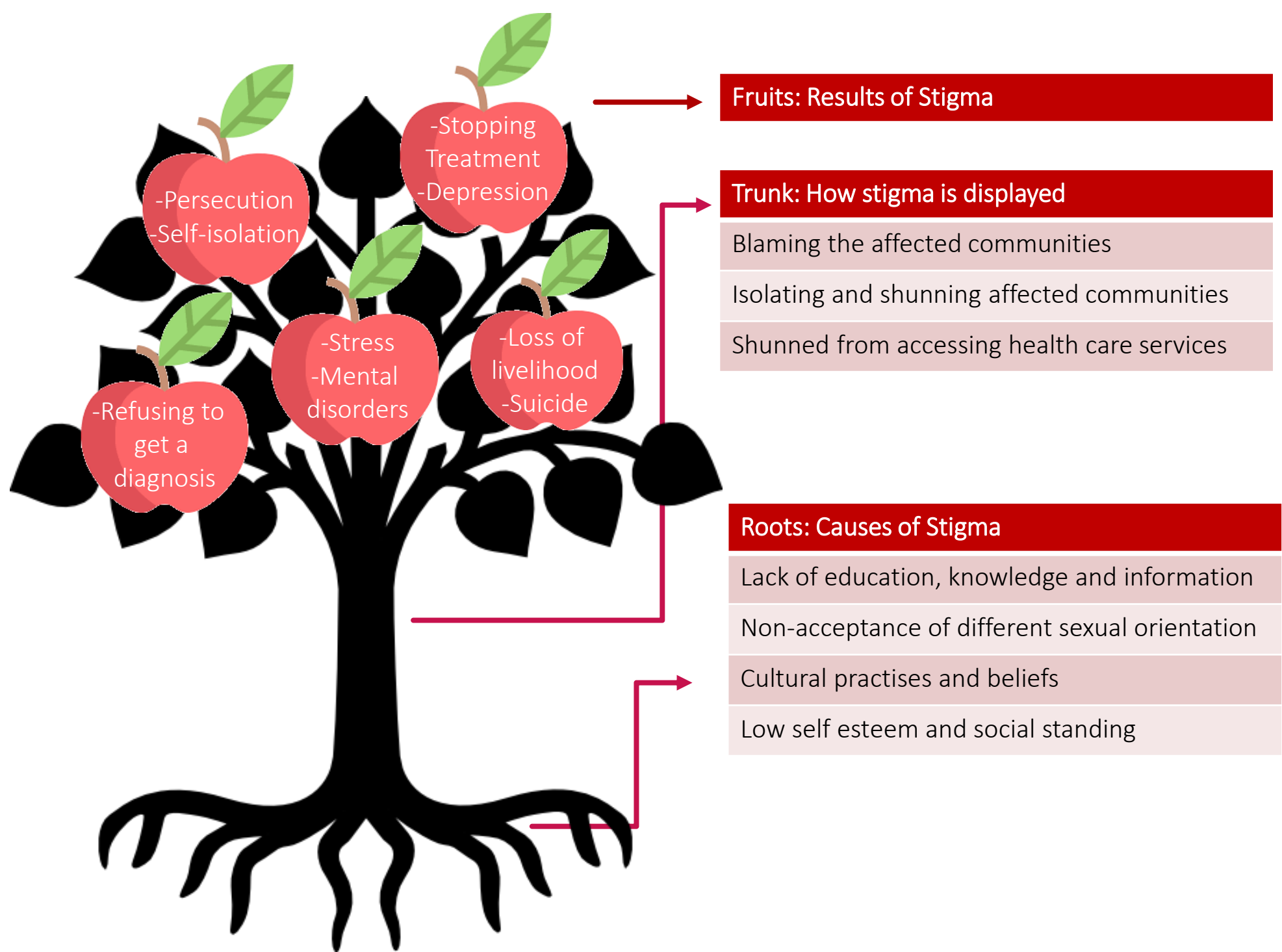| Developing Symptoms	Seeking Care	Getting a Diagnosis	Starting Treatment	Completing Treatment	Getting Cured	Getting Back on Track
Health System Barriers						
-No Knowledge -Stigma and Discrimination -No proactive case-finding from care givers	-Lack of ID card to access care for transgenders -Not all health facilities provide TB care -No out-reach from health facilities -Limited health facilities in remote areas -Low commitment from govt. for TB	-Lack of diagnostics -Lack of trained health staff -Lack of facilities for MDR TB -High patient turn over at health facilities	-Lack of counselling for patients -Insufficient drug availability -Lack of adherence support	-Lack of counselling for side effects -Lack of effective drugs with less side-effects	-Lack of effective free transportation services -Lack of access to a constant care provider -Rude & stigmatizing behaviour from health staff -Lack of peer support mechanisms -Long treatment cycles	-Lack of counselling to combat mental health problems
Community-level Barriers						
-No knowledge -Stigma and Discrimination	-Seeking care at alternate service providers	-Stigma and bullying -Self-stigma for diagnosis	-Feeling ashamed due to TB	-Side effects that cause distress	-Lack of financial resources to travel to the health facilities -Discontinuing treatment after 3 - 4 months - Stigma	-After being isolated it's difficult to re-join the community

Day 3: Becoming Change-Agents – Stigma and Advocacy

The sessions for the day were facilitated by GCTA Program Manager, Archana Oinam and focused on stigma and advocacy.
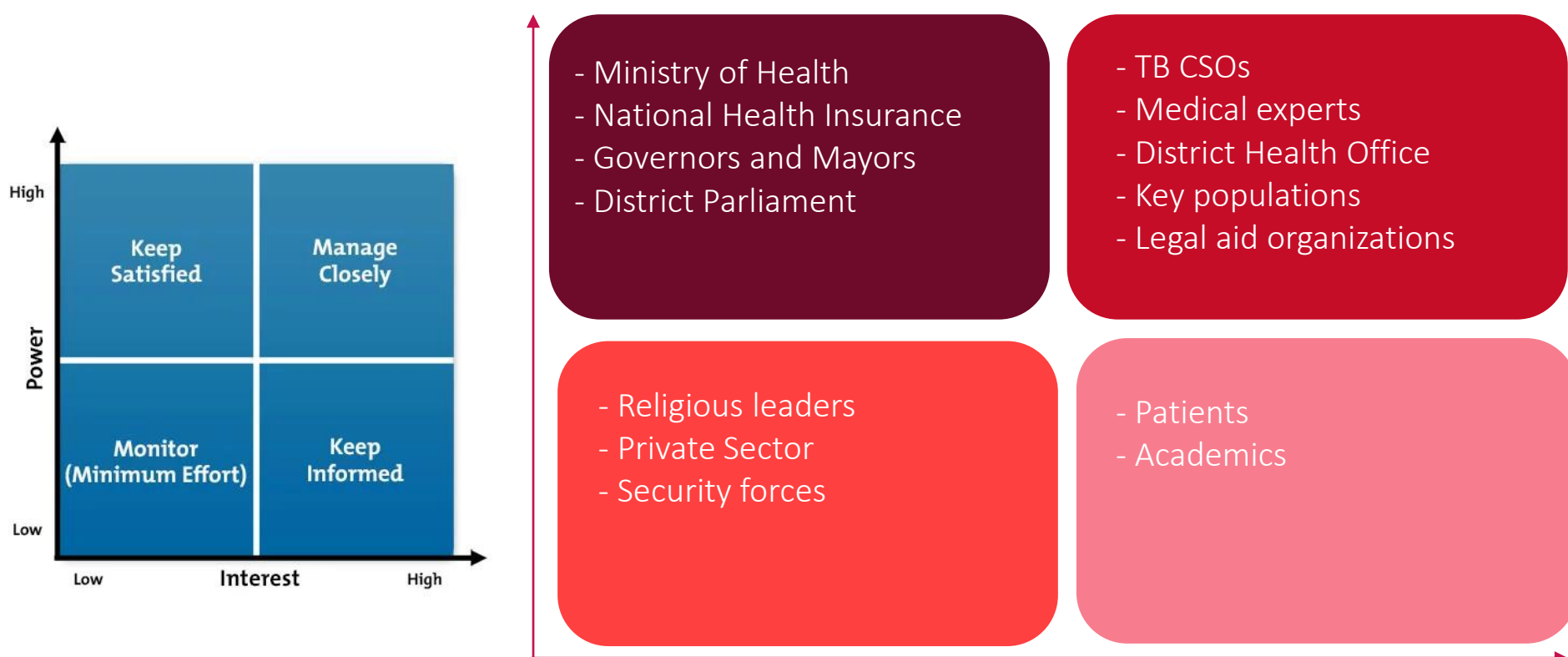
1.   Part 1 – TB & Stigma – "Problem Tree": This participatory exercise invited the participants to imagine the issue of stigma as a tree. They were then directed to divide themselves into groups and identify the roots, i.e. the causes of stigma, the trunk, i.e. how stigma is displayed and lastly the fruits, i.e. the results of stigma.

Fig 3: Stigma Tree

Fruits: Results of Stigma

-Persecution
-Self-isolation

-Stopping Treatment
-Depression

-Stress
-Mental disorders

-Loss of livelihood
-Suicide

-Refusing to get a diagnosis

Trunk: How stigma is displayed

Blaming the affected communities

Isolating and shunning affected communities

Shunned from accessing health care services

Roots: Causes of Stigma

Lack of education, knowledge and information

Non-acceptance of different sexual orientation

Cultural practises and beliefs

Low self esteem and social standing

2.   Part 2 – Advocacy Basics: Archana Oinam introduced the basics of advocacy and types of advocacy, advocacy frameworks and, tools and methods of advocacy in a participatory session.

3.   Part 3 – Stakeholder Analysis: This session dealt with definition of who is a stakeholder and invited the participants to work in groups to discuss stakeholder analysis and rank stakeholders as per their level of interest and power. This exercise empowered the participants to build focused advocacy plans tapping into the most favorable stakeholder resources.

Fig 4: Stakeholder Mapping

- Ministry of Health
- National Health Insurance
- Governors and Mayors
- District Parliament

- TB CSOs
- Medical experts
- District Health Office
- Key populations
- Legal aid organizations

- Religious leaders
- Private Sector
- Security forces

- Patients
- Academics

4.   Part 4 – Developing an Advocacy Plan: The participants put their learnings into action and devised advocacy plans by selecting an issue central to their community, identifying the resources and developing an action plan to combat the issue.

It takes strength to be an activist! Your primary responsibility is and always will be to the community you represent.

- Blessina Kumar

Day 4: Becoming Change-Agents – Communication Session

The last day of the training equipped the participants with tools of social media to further their advocacy strides. This session was led by GCTA Communications and Digital Media Officer, Priyanka Aiyer. The training came to a close with a feedback session from the participants and a valedictory session.

Training Evaluation

Almost all the participants (94%) except for one scored above 60% in the post test. Among them, two participants got all the answers correct and five got only one wrong. It can be concluded that knowledge and insights about TB treatment regime, access issues, gaps and challenges have been updated. Skills regarding advocacy and communication were enhanced. The participants were able to identify advocacy issues and each of them also developed an advocacy plan. Few of them also commented that they plan to conduct the similar training at the grassroots level and therefore the translation of the GCTA training manual in Bahasa Indonesia will be helpful.

Daily Feedback Form

Daily feedback was sought from participants to understand their engagement and if changes were required in the next day's agenda. The feedback was collected using forms where the participants were asked to give their ratings on the methodologies, duration and content of each session by rating each day's session as good/OK/poor.

The participants found almost all the content in the session to be useful and expressed that they would be using this in their work. However many of the participants felt that the time was limited for discussions and few of them felt that the trainer was fast in explaining the content.

Participant Feedback

I feel immensely lucky to be here. I am sure that now I will be able to help my transgender community to combat TB better and we will together bend the curve to make Indonesia TB free.

- Bety

One action can bring one change and one change can save one life. This training has empowered us to be agents of change and we will end TB together!

- Roylolo

A large section of the population in Medan is co-infected with TB and HIV. This training has empowered me to be able to help that community.

-Hendrick

Lessons Learned

- Working with a strong local partner makes the training process more efficient and effective.

- Selection of participants plays a very important role in the success of the training. The participants in this training were eager to learn and committed and were representative of key populations. Training turned out to be very effective because of their participation.

- Having skilled and motivated trainers adds to the quality of the training.

- Community members are the best Change-Agents to advocate for a more effective TB response and for a people centred rights based TB response in their respective set up. Similar trainings need to be replicated and conducted at decentralized level.

- Language was found to the barrier as all the trainers couldn't speak the local language and translation was required. The flow of discussions sometimes gets disturbed due to the translations being time intensive.

- Training hall set-up (physical space) and, the use of local ice breaker and games made the participants more participatory.