



National Tuberculosis Elimination Program

#EndStigmaEndTB

Strategy to End Stigma and Discrimination Associated with Tuberculosis



March 2021
Central TB Division
MoHFW
Government of India



Strategy to End Stigma and Discrimination Associated with Tuberculosis

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भारत सरकार
स्वास्थ्य एवं परिवार कल्याण मंत्रालय
निर्माण भवन, नई दिल्ली-110011

Government of India
Ministry of Health and Family Welfare
Nirman Bhavan, New Delhi - 110011

आरती आहुजा भा.प्र.से.

अपर सचिव

Arti Ahuja, IAS

Additional Secretary

Tel. : 011-23061066, 23063809

E-mail : ash-mohfw@nic.in

PREFACE

As a signatory to the Political Declaration from the first ever United Nations High Level Meeting on Tuberculosis (TB), India is committed to eliminating TB, an infectious disease that remains a major public health challenge in India. The Political Declaration acknowledges the enormity of the TB burden and its impact on people; it also acknowledges "stigma and discrimination because of the disease bring enormous costs for individuals affected by tuberculosis and their families". The Declaration reiterates the centrality of the need to address the stigma associated with TB, and thereby reduce the suffering of TB-affected communities.

India is committed to achieving TB elimination by 2025. However, we know that we cannot win the fight against TB if we do not first acknowledge and address both stigma and discrimination in a comprehensive manner. Even as we continue to invest in new tools and improve our delivery systems, we are also committed to strengthening our investment in communities and the provision of person-centered care.

In this context, and in keeping with our commitment to achieve TB elimination, I am very pleased to present the "Strategy to End Stigma and Discrimination Associated with Tuberculosis" in India. This document clearly acknowledges the extent of the impact of stigma on people with TB and establishes without doubt that stigma is a barrier to the elimination of TB. The strategy outlines the first steps towards ending stigma, by envisioning "a stigma-free TB response that enables India's goal of ending TB, reduced catastrophic costs, and higher acceptance and utilization of NTEP services".

I congratulate the National TB Elimination Programme and all stakeholders on the publication of this unique strategy document and look forward to working closely with all state governments to realise our dream of a stigma-free and TB-free society.

TB Harega, Desh Jeetega!



(Arti Ahuja)



विकास शील
संयुक्त सचिव
VIKAS SHEEL
Joint Secretary



सत्यमेव जयते

भारत सरकार
स्वास्थ्य एवं परिवार कल्याण मंत्रालय
निर्माण भवन, नई दिल्ली - 110011
Government of India
Ministry of Health & Family Welfare
Nirman Bhavan, New Delhi -110011
Phones : 23061481, 23063506 (T/F)
E-mail : sheelv@nic.in

MESSAGE

Tuberculosis (TB) is a socio-economic disease that requires a comprehensive response addressing the social and cultural aspects of the disease, in addition to the medical dimensions. One such critical social aspect is stigma and discrimination that are a reality for people affected by TB and their families. Although people with TB have suffered silently from stigma, there is considerable evidence to show that the impact of stigma, though often intangible, is long-term.

In recent years, as part of our community engagement strategy, we have witnessed first-hand the growing contribution of TB survivors and Champions, and the critical role they can play in addressing issues related to stigma in their communities. By speaking up boldly and openly about their TB experiences, these TB Champions have become powerful advocates and have been able to reduce the silence around TB.

This Strategy document is another crucial step towards our goal of a TB-free India and follows on from several recent policies introduced by the NTEP including the development of a gender-responsive framework and a multi-sectoral approach to TB. The End Stigma Strategy acknowledges the vital role of communities in ending stigma and discrimination. It identifies the need for a “cross-cutting strategy to ending stigma and discrimination in all TB interventions, with active and informed engagement of people affected by TB”.

I request all stakeholders to join hands and ensure this strategy is implemented in its true spirit, thus moving us closer to effectively ending stigma and discrimination associated with tuberculosis.

TB Harega, Desh Jeetega!

(Vikas Sheel)

टीबी हारेगा, देश जीतेगा - अधिक जानकारी के लिए संपर्क करें 1800-11-6666 (टोल फ्री)
TB Harega, Dese Jeetega - For more information contact 1800-11-6666 (Toll Free)
www.mohfw.nic.in

Dr. Sudarsan Mandal
MD (SPM)

Addl. DDG (TB), Central TB Division

Tel. (O) : 011-23061130

E-mail : mandals@rntcp.org



Government of India
Ministry of Health & Family Welfare
Room No. 532-C, Nirman Bhawan,
Maulana Azad Road, New Delhi-110011

MESSAGE

Stigma associated with tuberculosis is a significant barrier that can prevent people with TB symptoms from seeking health care services. If we are to reduce delays in diagnosis and improve treatment outcomes – both critical to ending TB – we must take all possible efforts to mitigate both stigma and discrimination within health systems and society as a whole. As people with TB move through the care cascade – from the onset of symptoms to diagnosis and treatment and to life after TB – they must experience an enabling, supportive environment free of all stigma and discrimination.

This Strategy document thus presents, a comprehensive approach to addressing stigma and discrimination. Through this Strategy, the NTEP is committed to a three-fold approach to mitigating stigma – in the community, at workplaces and at health care facilities. We are also looking to improve the quality of data available on stigma and to establishing rigorous measures to assess and evaluate stigma, and its impact.

I call on every single member of the NTEP at all levels to commit to upholding the values outlined in this document. I acknowledge the contribution of all partners who have supported the NTEP in the development of this unique strategy document and reiterate the TB programme's commitment to achieving a TB-free, stigma-free India by 2025.

TB Harega, Desh Jeetega!


(Dr Sudarsan Mandal)

" It's Time To End TB " "TB Harega Desh Jeetega "

Message

India's National Strategic Plan for 2020-25 outlines the country's priorities to achieve TB elimination. The NSP calls for a transition from 'passive community participation to meaningful engagement and ownership, with reliance on TB champions and TB Survivors' and proposes a strategic investment in TB forums which are effective change agents able to work at reducing/eliminating stigma and establishing a rights based TB response.

The development of this strategy is an important step, but merely the first one – the real work lies ahead, to operationalize the strategy and get all stakeholders involved. Addressing stigma is not the sole responsibility of the NTEP nor of the community – every single actor who plays a role in India's TB response has an equal role to play in addressing stigma. This includes private sector providers who must provide person-centred, non-stigmatizing services; employers of vulnerable populations who must put in place measures to ensure a non-discriminatory workplace; educational institutions that must protect the privacy and confidentiality of children affected by TB; the media that must adopt non-stigmatizing language to write about people with TB; and all our civil society partners, who must integrate stigma mitigation into their projects, irrespective of whether they are working with the private sector or in strengthening diagnostics or with the community.

I am confident that the effective implementation of this Strategy will take us closer towards ensuring that every person affected by TB receives the highest quality of care and to realizing our collective dream of making India TB Free.

TB Harega Desh Jitega! #EndStigmaEndTB



(Ms Blessina Kumar)

The Global Coalition of TB Activists

Acknowledgements

The Strategy to End Stigma and Discrimination Associated with Tuberculosis is intended to inform and guide all stakeholders on the planning and implementation of activities that will prevent, reduce and end the stigmatisation and discrimination of people affected by TB in India. The document was developed and published through a collaborative process led by the Central TB Division (CTD), Ministry of Health and Family Welfare, Government of India. The technical development and content of this document was supported by NTEP partners – Abt Associates, ALERT India, Global Coalition of TB Activists (GCTA), Global Health Strategies (GHS), Karnataka Health Promotion Trust (KHPT), Resource Group for Education and Advocacy for Community Health (REACH), Storytellers, TB Alert India, The Union, and the United States Agency for International Development (USAID). Sections of the document were drafted by Dr Oommen George with inputs from CTD and partners.

We thank and acknowledge the valuable contribution of all partners who supported this process. We thank the REACH team for coordinating the design, layout and printing of the document. Our sincere gratitude to the United States Agency for International Development (USAID) for supporting the development of this document through their partner REACH.

Acronyms

ACSM	Advocacy, Communication and Social Mobilization
CB-NAAT	Cartridge-based Nucleic Acid Amplification Test
FLW	Front Line Worker
HCP	Health Care Provider
HIV	Human Immunodeficiency Virus
IC	Inner Circle (of person with tuberculosis)
IPC	Inter-personal Communication
LTBI	Latent Tuberculosis Infection
NA	Not Applicable
NFHS	National Family Health Survey
NSP	National Strategy Plan (for tuberculosis elimination)
NTEP	National Tuberculosis Elimination Program
PwT	Person with Tuberculosis
SC	Social Circle (of person with tuberculosis)
STCI	Standards for Tuberculosis Care in India
STP	Stop TB Partnership
TB	Tuberculosis
TSG	Treatment Support Group
WHO	World Health Organization

Purpose of the Document and its Target Audiences

The purpose of this document is to inform NTEP stakeholders on the program's strategy to end stigma and discrimination associated with TB. This document will guide users in the planning, development, and carrying out of activities that prevent, reduce and put an end to stigmatization and discrimination of people with, or affected by, TB.

This Strategy to End Stigma and Discrimination Associated with Tuberculosis:

- Sensitizes stakeholders on stigma and discrimination, its impact on people affected by TB, and on why it is critical to end stigma so as to eliminate TB;
- Provides an understanding of the drivers and facilitators of stigma associated with TB;
- Identifies and prioritizes context specific interventions to end stigma and discrimination in different settings and among specific target audiences; and
- Recommends ways to measure stigma-related intervention outcomes and impact at the national level.

The End Stigma Strategy is meant for anyone involved in improving the quality of TB care and working towards TB elimination in India. It is therefore pertinent for NTEP program managers at national, state or union territory, and local government levels. It is also pertinent for partner organizations such as non-government organizations, consulting agencies, academia and educational institutions, professional associations, corporate partners, etc.

Using this Document

Stigma primarily stems from fear of TB, and of the disastrous health, financial, personal, and social consequences of the disease on affected individuals and families. Stigma exacerbates the medical and social hardships of TB, and is responsible for delays in diagnosis and treatment initiation, treatment interruptions, and poor outcomes. **Stigma is a barrier to TB elimination.**

Keeping this in mind, the vision, goal, principles, objectives, and guidelines, outlined in this strategy document, must become relevant and/or be adopted by all people affected by TB – persons with TB, their close family members and friends ('inner circle'), their personal and work acquaintances ('social circle'), members of the community and community influencers, and health care service providers and their influencers. To make this beneficial for individual members of society, **NTEP program managers at state and district levels need to plan and fine-tune interventions**, with relevant input from people affected by TB in their coverage area, and with the help of local community-based and civil society organizations.

NTEP officials should ensure that micro-plans are developed for roll out of this Strategy to End Stigma and Discrimination Associated with Tuberculosis, with **Operational Guidelines for Advocacy, Communication, and Community Engagement**, all of which include realistic monitoring and evaluation plans guided by this document.

Executive Summary

India's National Strategic Plan (NSP) for elimination of tuberculosis (TB) proposes bold strategies with commensurate resources to rapidly decline TB incidence and deaths by 2025, five years ahead of the global End-TB targets and Sustainable Development Goals. Its **vision is for a TB-Free India with zero deaths, disease and poverty due to TB, and its goal is to achieve a rapid decline in the burden of TB morbidity and mortality, while working towards elimination of TB in India by 2025.**

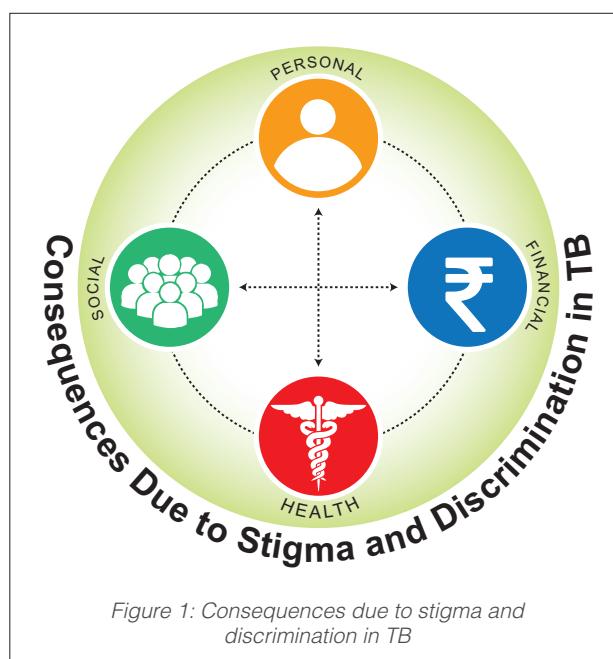
There remain several challenges and barriers in the path towards TB elimination, with some even preventing access to quality TB services and care. A major barrier continues to be the stigma and associated discrimination experienced by persons with or affected by TB. These are recognized as commonly identified human rights related barriers hindering the fight against the TB epidemic.¹ Stigma impacts people with TB, their families and friends – personally, socially, financially and physically (Figure 1).

Stigma primarily stems from fear of TB, and of the disastrous health, financial, personal, and social consequences of the disease on affected individuals and families. **Stigma exacerbates the medical and social hardships of TB, and is responsible for delays in diagnosis and treatment initiation, treatment interruptions, and poor outcomes. Stigma is a barrier to TB elimination.**

There are several types of stigma associated with TB. It may be perceived (or anticipated) or experienced (or enacted). Stigma also operates at different levels: in communities, in close social networks and institutions, including health care establishments. Stigma may also be internalized by those affected.

Efforts towards elimination of TB need to involve social interventions along with medical and public health interventions. India's National TB Elimination Program (NTEP) recognizes the need to address the dynamic social, environmental, economic, human rights and gender drivers of the disease through empowering and meaningfully engaging TB survivors and affected communities.

The NSP calls for interventions to address stigma and discrimination faced by persons with or affected by TB. This document, which is aligned with the NSP, describes why it is important to end stigma, and what needs to be done to remove and prevent stigma and discrimination in the context of TB elimination. The End Stigma Strategy's **vision is of a stigma-free TB response that enables India's goal of ending TB, reduced catastrophic costs, and higher acceptance and utilization of NTEP services.**



1. Ethics guidance for the implementation of the End TB Strategy. Geneva: World Health Organization; 2017 <https://www.who.int/tb/publications/2017/ethics-guidance/en/>

There are four principles that are invoked in this strategy to prevent or reduce the consequences of stigma, negate its disproportionate effects, and justify the need to invest in efforts to end TB stigma; each affects a specific set of people:

1. People with TB and those close to them, their inner circle, are able to live with TB and access TB services without being judged.
2. People in the social circle of TB-affected persons and members of the community do not fear TB, but are assured that it is a treatable disease, and that their support of persons with TB will result in early and better recovery, and thus prevent its transmission to others.
3. Community influencers contribute to fostering of safe and acceptable environments; their actions promote positive social behaviors towards people affected by TB.
4. Health care service providers and health influencers adopt standards for TB care and their capacity in using stigma-mitigating soft-skills and language is built.

The NTEP also recommends certain overarching actions, or strategic priorities:

1. NTEP partners, stakeholders, and implementers, adopt the vision of a stigma-free TB response and appropriately align interventions to the goal to end stigma and discrimination faced by people affected by TB, through all stages of the continuum of care.
2. Empower and engage people affected by TB in the drive towards ending TB related stigma and discrimination.
3. Interventions for ending TB related stigma and discrimination target drivers and facilitators of stigma, and stigma manifestations and practices.
4. To maximize impact, plan for multipronged stigma-mitigating interventions and target all layers of the socio-ecological model of influence.
5. To begin, focus on ending stigma and discrimination in key settings, and at points in the TB care cascade that have the highest impact on improving desired outcomes.
6. Review messages and strategies used for improving awareness about TB and incorporate messages aimed at ending stigma and discrimination.

Section 1: Introduction

Tuberculosis (TB) is a communicable disease, and one of the top 10 causes of death worldwide. Caused by *Mycobacterium tuberculosis*, a bacterium that spreads from an infected person through the air, it is the leading cause of death from a single infectious agent. TB typically affects the lungs and is usually curable with a course of antibiotics. TB is also a well-documented social disease. It can be prevented by driving down the prevalence of risk factors, such as smoking, alcoholism, under nutrition, diabetes and HIV infection, and poverty and overcrowding.

TB can be managed and eliminated by early detection and effective treatment, but to be sustained, this needs to be done in ways acceptable to those affected.

Globally, an estimated 10 million people fell ill with TB in 2019; about 3 million of whom remained undiagnosed or unreported.² This resulted in about 1.4 million deaths. India carries over a fourth of this burden with an estimated total number of 2,690,000 new cases, averaging an incidence rate of 199 per 100,000 population, in 2019.

Stigma and discrimination are recognized to be among the most common human rights-related barriers hindering the fight against the TB epidemic.³ In September 2018, Heads of State and Governments at the United Nations

High-Level Meeting on TB, and in the resulting Political Declaration on the Fight to End TB,⁴ committed to promoting and supporting an end to TB stigma and all forms of discrimination.⁵ This commitment demonstrates recognition at the highest level that ***to end TB, we must end TB Stigma.***

The National Strategic Plan (NSP) for Tuberculosis: 2017-2025; Elimination by 2025, speaks loudly for interventions to address stigma and discrimination faced by persons with or affected by TB. Broad suggestions articulated in the NSP include using advocacy, communication and social mobilization (ACSM) activities to combat stigma and discrimination; designing and using 'high visibility, high decibel' communication campaigns; sensitization of media and program staff on avoiding stigmatizing language; conducting research around stigma and converting evidence to action to prevent or reduce stigma; ensuring stigma-free and community sensitive TB services; and preventing intangible costs attributed to stigma.⁶ This ***Strategy to End Stigma and Discrimination Associated with Tuberculosis*** describes how stigma and discrimination can be removed and prevented to benefit people with TB, and those involved in TB care. It applies to all organizations and individuals involved in TB care and prevention in India.

2. *Global TB Report, 2020*

3. *Ethics guidance for the implementation of the End TB Strategy*. Geneva: World Health Organization; 2017 <https://www.who.int/tb/publications/2017/ethics-guidance/en/>

4. *Political declaration of the high-level meeting of the General Assembly on the fight against tuberculosis (A/RES/73/3)*. New York: United Nations General Assembly; 2018 https://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/73/3

5. *UN High-Level Meeting on TB key targets and commitments for 2022*. Geneva: Stop TB Partnership; 2018 http://www.stoptb.org/assets/documents/global/advocacy/unhlm/UNHLM_Targets&Commitments.pdf

6. *National Strategic Plan (NSP) for Tuberculosis: 2017-2025; Elimination by 2025*

Section 2: Stigma and its Impact on Persons Affected by TB

“I wondered, God! Why did I get this... it is better for me to die, than to live with this illness” [a person with TB (PwT)]

TB has for centuries been treated as a fatal illness resulting in prejudice, discrimination, and isolation. It has been showcased through a lens of foreboding and stereotypes, even in Indian cinema. Stigma around TB tends to be latent and manifests when someone is known to have the disease. Stigmatizing attitudes are present in 73 percent of the Indian population, and discriminatory attitudes toward persons with TB, in 98 percent.⁷

What is stigma?

Stigma is described as a phenomenon whereby an individual with an attribute that is deeply discredited by her/his society is rejected as a result of that attribute.⁸ It is a process by which the reaction of others impacts normal identity and disqualifies the individual from full social acceptance. WHO defines stigma 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.

Stigma harms the livelihoods, and health of individuals and their families who experience it, and severely hinders TB responses. It exacerbates the medical and social hardship

of TB and acts as a barrier to accessing treatment care and support. When the surrounding environment is stigmatizing and discriminatory, it begins to push those with TB to stigmatize themselves. People who fear losing their jobs, their loved ones, or being kicked out of school or their homes because of TB are less likely to seek testing and treatment for the disease, making the already challenging response even more difficult. Stigma and discrimination are not only human rights violations; they are a fundamental cause of population health inequalities. To end TB everyone must recognize it as such and work together to eliminate TB stigma.⁹

Drivers and facilitators of stigma.

The main reasons/drivers for stigma are:

1. **Fear of TB infection**, the sub-text being the belief that TB will never be cured, that its treatment is long and drawn out,



VOICES ON
STIGMA

...from people with TB

“I could not get a loaf of bread from the store near my house because they didn’t want to sell to me... I isolated myself... I could not bring myself to share my pain with my friends... I lost my job and was thrown out of my house...” [PwT; a man]

7. Sagili, KD, Satyanarayana S, and Chadha SS. 2016. “Is Knowledge Regarding Tuberculosis Associated with Stigmatising and Discriminating Attitudes of General Population towards Tuberculosis Patients? Findings from a Community Based Survey in 30 Districts of India.” *PLoS ONE* 11(2): e0147274. <https://doi.org/10.1371/journal.pone.0147274>

8. Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity*. New York, New York: Simon & Schuster, Inc.

9. Addressing TB Stigma on Zero Discrimination Day; http://www.stoptb.org/news/stories/2019/ns19_009.asp

and the feeling that it eventually leads to death. A related fear is that TB leads to economic disaster. Some fears are based on or aggravated by myths, such as that TB is a hereditary disease, or a curse.

2. **Belief that TB will not affect them:** As TB is believed to be a disease of the very poor, with the image of an 'emaciated man with sunken eyes who is coughing blood', many believe that they or their family members will never get TB.
3. **Prejudice about the person with TB,** and believing that the disease afflicts those who do 'bad things'.
4. **Belief that it (stigmatizing behavior) is the societal norm:** doing what others, who stigmatize and discriminate against persons with TB, do.

While the above drivers trigger or aggravate stigma, there are environmental factors that facilitate discrimination and other manifestations of stigma. These include cultural, social and gender norms, health policy and standards, and legal and statutory conditions applicable in the country.

Developments in medicine, including in public health, have drastically improved treatment outcomes and quality of life of people with TB. However, like with several other medical conditions such as dementia, mental health conditions, HIV, etc., persons with, and those closely affected by TB, also suffer from the far-reaching, catastrophic, but preventable complexities caused by stigma.

Stigma has consequences on the mental, social, personal, emotional, physical, and financial health of persons with TB, and also on those who are affected, such as their

families. These consequences influence each other, leading to an overall adverse domino effect. The existing discrimination due to cultural diversities and economic inequities gets compounded when affected by a disease already associated with myths.

Stigma and discrimination affect men and women differently. Both report similar emotional and social symptoms, but women often feel more distressed, especially around arranging marriages, social isolation, and inability to care for their children and family. Men on the other hand are more troubled by loss of jobs and income.¹⁰

A study has shown that due to stigma, 60 percent of persons with TB hide the disease from friends and neighbors, and that it harms their behaviors, emotions, relationships, and finances.¹¹ These consequences delay TB diagnosis, affect treatment outcomes, and have an impact on the health of individuals and their families. Studies have also shown that stigmatizing behavior does not reduce with increased knowledge about TB. A 1999 study concerning mental health concluded that while stigma was expected to abate with increased knowledge, just the opposite occurred: stigma in some ways intensified, even though understanding improved.¹² The essence of this conclusion is reflected in a more recent study, which concludes that



VOICES ON
STIGMA

...from people with TB

"At my workplace, people no longer wanted to share my lunchbox; they would avoid me... I induced myself to self-stigma because I was feeling very guilty..." [PwT; a woman]

10. Atre, SR., Kudale AM., MorankarSN., Rangan SG., and Weiss MG. 2004. "Cultural concepts of tuberculosis and gender among the general population without tuberculosis in rural Maharashtra, India." *Trop Med Int Health*. Nov; 9(11): 1228-38. <https://www.ncbi.nlm.nih.gov/pubmed/15548321>

11. Dhingra, VK and Khan S. 2010. "A sociological study on stigma among TB patients in Delhi." *Indian J Tuberc*. 57:12-8. <https://www.ncbi.nlm.nih.gov/pubmed/20420039>

12. Mental health: A report of the Surgeon General. U.S. Department of Health & Human Services; Bethesda, MD: 1999. https://archive.org/stream/mentalhealthrepo00unit/mentalhealthrepo00unit_djvu.txt

stigmatizing and discriminatory attitudes toward TB patients remain high among the general population in India and that these attitudes are independent of the knowledge regarding TB. It adds that the knowledge disseminated about TB is mainly medical, and may not adequately address the factors that lead to stigma and discrimination toward persons with TB.¹³ One publication suggested a paradigm shift in TB care, concluding that programs need to address social dimensions of TB and adhere to the principles of good care with the same commitment that is devoted to ensuring that people with TB follow treatment guidelines.¹⁴

Stigma negatively impacts everyone affected by TB. However, it disproportionately hampers equitable access to quality services among priority populations defined under the NSP,¹⁵ including those who are socially vulnerable and those with high clinical risk of acquiring TB. The NSP defines these groups under 3 categories:

1. **People who have increased exposure to TB** due to where they live or work: including prisoners, sex workers, slum dwellers, miners, hospital visitors, healthcare workers, factory workers, construction workers, and community health workers.
2. **People who have limited access to quality TB services:** including migrant workers, women in settings with gender disparity, children, geriatric populations, physically challenged persons, tribals, people living in hard-to-reach areas, conflict affected areas, refugees or internally displaced people, illegal miners, and undocumented migrants.

3. **People at increased risk of TB because of biological or behavioral factors** that compromise immune function: including people with HIV, diabetes or silicosis, those undergoing immunosuppressive therapy, those who are undernourished, use tobacco, suffer from alcohol-use disorders, and those who inject drugs.

There is a need to build a solid voice of reason by addressing reasons for stigmatization and discrimination. This can be done by creating and engaging people exhibiting positive behaviors to influence others. This cross-cutting change, implemented with collaborative effort, is needed to put an end to stigma and discrimination faced by persons with or affected by TB.



...from people with TB

“My family members keep a distance... Everything is separated... I cook for myself, and wash my own dishes and clothes...” [PwT; an older woman]

“My grandchildren and children are innocent and should not get infected through me...” [PwT; an older man]

Types of Stigma

Stigma associated with TB is complex; it may be perceived (or anticipated), experienced (or enacted), or even be internalized by one who is affected. For the sake of uniformity, this strategy document uses types and definitions adopted by the Stop TB Partnership's TB Stigma Assessment Implementation Handbook,¹⁶ which in turn refers to the TB

13. Sagili, KD, Satyanarayana S, and Chadha SS. 2016. “Is Knowledge Regarding Tuberculosis Associated with Stigmatising and Discriminating Attitudes of General Population towards Tuberculosis Patients? Findings from a Community Based Survey in 30 Districts of India.” *PLoS ONE* 11(2): e0147274. <https://doi.org/10.1371/journal.pone.0147274>

14. Ogden, J., Rangan S., Uplekar M., Porter J., Brugha R., Zwi A., and Nyheim D. 1999. “Shifting the paradigm in tuberculosis control: illustrations from India.” *Int J Tuberc Lung Dis*. Oct;3(10):855-61. <https://www.ncbi.nlm.nih.gov/pubmed/10524581>

15. Chapter 8, Priority Populations; *National Strategic Plan for Tuberculosis: 2017-25 Elimination By 2025*

16. Stop TB Partnership's TB Stigma Assessment Implementation Handbook; <http://www.stoptb.org/assets/documents/communities/STP%20TB%20Stigma%20Assessment%20Implementation%20Handbook.pdf>

Stigma Measurement Guidance published by the USAID supported Challenge TB project.¹⁷ The types of stigma described are:

1. **Internalized or self-stigma:** This captures the idea that TB-affected individuals may come to absorb or endorse negative stereotypes, and therefore behave or think according to false portrayals and negative messages.
2. **Anticipated stigma (perceived stigma):** This is the worry that one will be devalued after a TB diagnosis. For the person with a TB diagnosis, this is the fear – often the result of observing others being stigmatized – that the stigma against the person will be so bad that it will affect access to TB services. It may delay people from seeking and returning for care, or impact adherence to the prescribed medicines. Whether or not stigma actually occurs, anticipated stigma may interfere with care seeking and treatment adherence.
3. **Enacted or experienced stigma** reflects the range of stigmatizing behaviors, messages, and effects that are either directly experienced by the person with TB or by their families and/or that drive others – in particular: members of the person’s family, community, health care providers, and people at the person’s workplace – to acts of discrimination, rejection, or isolation in different settings. Enacted and experienced stigma is two sides of the same coin, either seen from the perspective of the stigmatizer (enacted) or the stigmatized person (experienced).
4. **Secondary stigma** refers to the idea that caregivers, friends or family members may expect negative attitudes or rejection because of their association with the disease and/or persons with TB. Furthermore, this may dictate their

behaviors or beliefs, regardless of whether stigmatizing attitudes or reactions actually occur.

5. **Community/public stigma** describes negative attitudes, beliefs and behaviors held by the wider community – neighbors or co-workers in particular – or general public. This is closely related to anticipated stigma.
6. **Structural stigma** describes the laws, policies, media and institutional architecture that may be stigmatizing or alternatively protective against stigma. This includes societal level conditions, cultural norms and institutional practices that constrain the opportunities, resources and wellbeing of stigmatized populations.



...from people with TB

“I’m ashamed if I have to wear a mask in public...”
[PwT; a young woman]

“I was not certain that I would pull through the long months of treatment...” [PwT; a man]

“I faced so many problems... I lost my job– they told me they didn’t need me anymore and that I should rest at home... There was lot of gossip... Even my in-laws reacted meanly... It upset me and I hated myself...” [PwT; a woman]

“I was 14 and appearances mattered a lot... I began questioning myself... The fear of discrimination was always on my mind, and I was determined not to disclose that I had TB...” [PwT]

17. Challenge TB. TB stigma measurement guidance. The Hague: KNCV; 2018
https://www.challengeTB.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf

Reasons to Invest in Reducing TB-related Stigma and Discrimination

There are three strategic reasons to invest in reducing TB-related stigma and discrimination, both to halt the process that results in stigma and discrimination, and to mitigate their adverse consequences:

1. Higher acceptance and utilization of NTEP services. Ending stigma and discrimination associated with TB, reduces, or may even remove, the fear associated with the disease. This, in turn, will lead to greater acceptance to NTEP services, be it through public or private health care sectors, and improved access to quality care.
2. Reduced catastrophic costs and better use of resource. Higher acceptance and utilization of NTEP services will result in early and more universal screening and testing, and diagnosis of TB, and even to improved treatment adherence and outcomes. Individual out-of-pocket expenditure, especially catastrophic costs, can be minimized and program resources can be streamlined with greater efficiency and effectiveness.
3. Better realization of India's goal of TB elimination. Ending stigma entails a series of actions that results in early and universal TB diagnosis and improved treatment outcomes. This is therefore an important component of a bouquet of interventions needed to eliminate TB.



VOICES ON
STIGMA

... from close family & co-workers

"Our biggest fear was how people would react to our daughter's illness... We avoided telling anyone... We did not want our family to get ostracized, but it's difficult to hide... We did it to protect her..."
[a father]

"I had an effective team member with TB. He hesitated to seek leave. When he did, with great difficulty, I gave him 2 months... But, other team members felt I should replace him as it's not OK for him to rejoin..." **[a supervisor]**

"My wife [who has TB] is the cause of additional expenditure." **[a husband]**

"I was so scared when my son was diagnosed with TB. I thought he would die" **[a mother]**

... from community members

"I have seen how my neighbor, a young boy of 26 years, was kept away by his family, with everything separate..." **[community member]**

"I know a family in my neighborhood whose lives were shattered due to TB. They had no money, and even the children were taken out of school. I definitely do not want this to happen to my family. I am completely staying away from the affected family, so that I do not get TB" **[community member]**

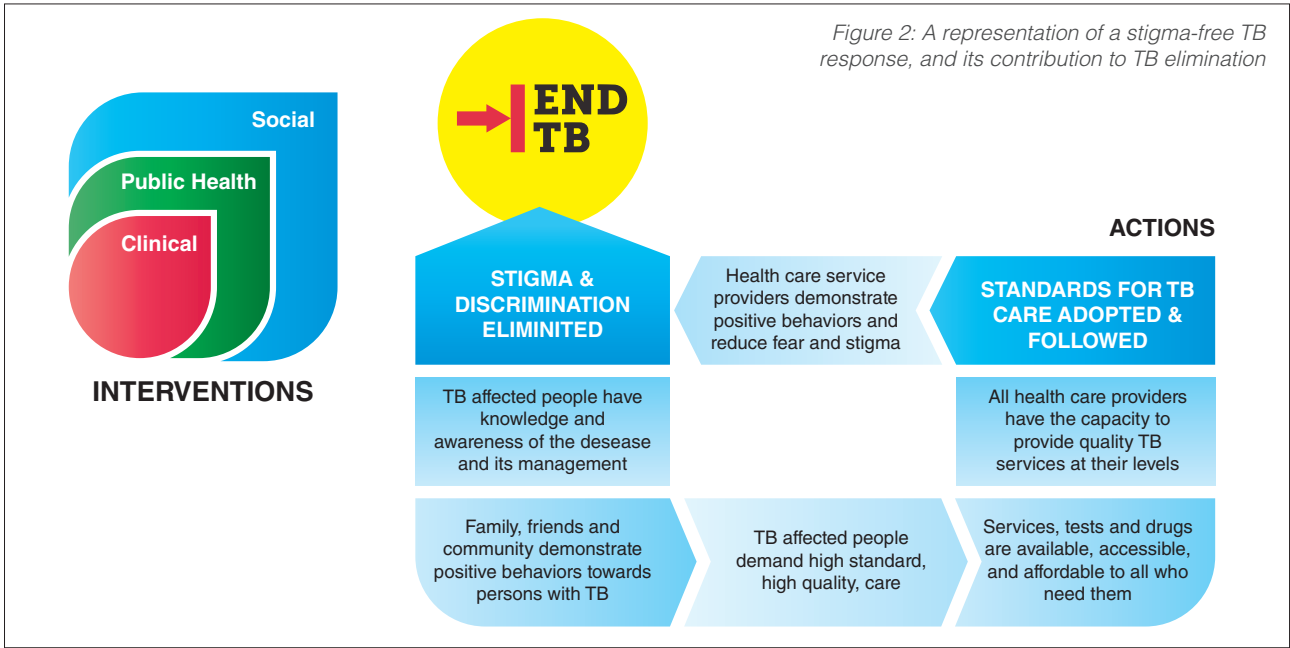
... from health service providers

"They don't share the [TB] disease status...they are not asking family members to seek a TB test..."
[community care provider]

"Patients ask me if they'll ever be cured. They think that once they are affected, TB will never go away"
[a doctor]

Section 3: Vision, Goal, and Objectives of the End-stigma Strategy

Addressing stigma and discrimination, with **a vision of a stigma-free TB response that enables India’s goal of ending TB, reduced catastrophic costs, and higher acceptance and utilization of NTEP services** is a critical step towards the realization of India’s goal of TB elimination by 2025 (Figure 2). To be effective, the management of TB needs to be social as well as medical, with each complementing the other. Standards for TB care in India (STCI) need to be augmented to include standards aimed at preventing, reducing, and removal of stigma and discrimination, and the program should ensure that all TB service providers effectively and uniformly adopt these standards. The **goal is to end stigma and discrimination faced by persons with or affected by TB, through all stages of the continuum of care.**



Reduction of stigma and discrimination, addressed through a gender lens and administered differently among men, women, and persons identifying themselves under other gender labels, helps delivery of equitable TB care services, empowering otherwise disadvantaged persons address consequences of TB disease.

The objectives of this vision are:

1. Advocate for resource investments to end stigma and discrimination associated with TB by 2025.
2. Adopt, build capacity, and incorporate a cross-cutting strategy for ending stigma and discrimination in all TB interventions, with active and informed engagement of people affected by TB.

3. Develop and execute a communications strategy, using multiple media and formats, addressing various dimensions of TB-related stigma and discrimination.
4. Design and support the roll out of community-led interventions that mobilize societies to foster non-stigmatizing and non-discriminating behaviors towards persons with or affected by TB.

Principles Behind the Recommended Strategic Interventions

The strategic interventions described in this document are written against the background of the TB care cascade (continuum of care), and keeping in mind the target audiences for advocacy, communications, and community engagement. The **principles behind the interventions to prevent or remove stigma** and discrimination due to TB vary by target audience, and include:

1. Persons with TB and members of their inner circle (those that are invested in persons with TB; together referred to as persons affected by TB) should be able to live with TB, without being judged. They need to feel that they can access quality TB services in environments that are safe. To enable this sense of security among TB-affected persons, the NTEP and its implementers need to:
 - a. Remove fear of TB by improving awareness, normalizing the disease, and casting out myths;
 - b. Build confidence among people affected by TB that information concerning them is safe (confidential) and will not be misused;
 - c. Empower TB survivors and engage them in advocacy, communication and community engagement activities, thereby establishing a ground-up approach to solve real problems faced by those affected by TB;
- d. Communicate and amplify key messages through positive deviants from the inner circle of persons with TB;
- e. Promote effective provider-patient dialogue by ensuring that quality TB care services are available, accessible and affordable to all, and that the quality of care is acceptable to TB-affected persons. This will enable affected persons to seek timely health care, accept provider advice and support, and reach out when faced with conditions threatening to disrupt treatment compliance. This will also help streamline contact screening, testing, and preventive treatment.
2. People in the social circle of TB-affected persons (those who directly engage with them, but are not invested) and members of the community should not fear TB, but be assured that it is a treatable disease, and that their support of affected persons can contribute to early and better recovery. Interventions for this target audience should:
 - a. Improve awareness about TB, normalize the disease, and remove myths and fears. This will enable reduction in the spread of TB through symptom recognition and early health seeking, and through preventing the disease itself;
 - b. Use positive deviants among the social circle to amplify messages promoting support to people affected by TB.
3. Community influencers, including community and political leaders, and celebrities, should actively contribute to the establishment of a safe and acceptable environment for TB-affected persons. They should promote elimination

of stigma through their messages, action, and amplification of positive messages that aid in removing fears, myths and prejudices. Their actions should encourage conversations on TB in political and media forums, and through celebrity voices, to promote positive behaviors that normalize TB in communities.

4. Health care service providers and health influencers should adopt clinical, public health and social standards for TB

care, thus improving access to quality services and treatment. Their capacity in using appropriate soft-skills and non-stigmatizing language should be improved through education. Equitable patient-friendly services and counseling should become the health service norm, and fear among health personnel should be mitigated through improved protection of health staff, and provision of timely and effective care, when required.

Section 4: The Implementation Framework

This document uses the **Health Stigma and Discrimination Framework**, and the Socio-Ecological Model of influence for framing recommendations and identifying target audiences for ending stigma and discrimination associated with TB.

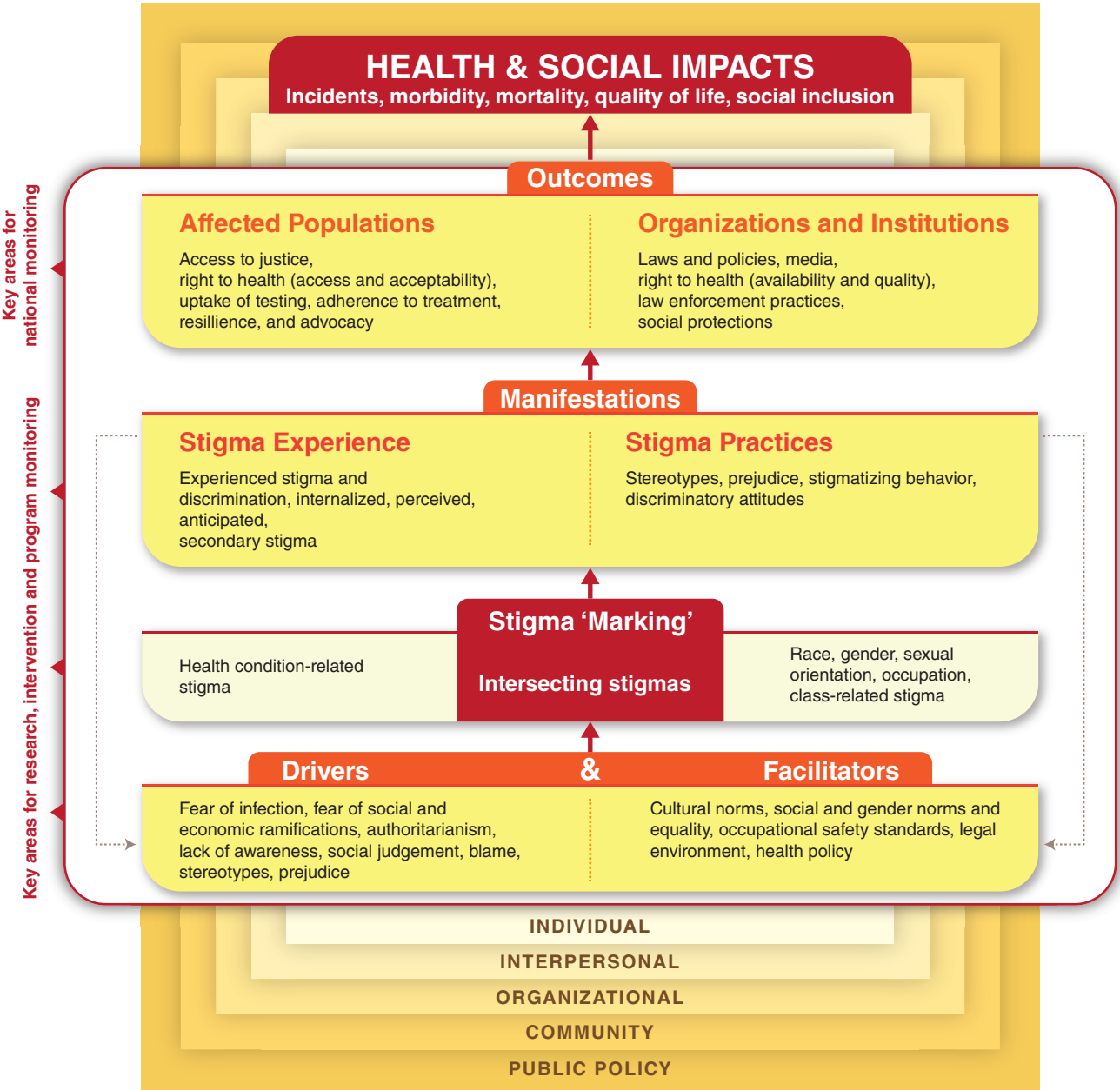


Figure 3: Health Stigma and Discrimination Framework

Target Audiences using a Socio-Ecological Model of Influence

The socio-ecological model of influence (Figure 3) is a theory-based framework for understanding the multiple levels of a social system, and interactions between individuals and the environment within this system.¹⁸ It is used here to understand how stigma influences people who are directly or indirectly connected to persons with TB. It details how stigma and discrimination are perceived or felt by people affected by TB, including persons with TB disease, their families and friends, and those who are emotionally invested in such persons, and how it influences others who are not so invested, but who, out of fear or prejudice, behave in ways that adversely impact those affected by TB.

Person with TB, and Person with Presumed TB

Persons with TB are those with TB disease, and persons with presumed TB are those with symptoms and/or signs of TB: they include persons with, or with presumed, TB of the lungs or of other organs. These terms do not differentiate between persons with drug-sensitive and drug-resistant TB disease, and do not include persons with latent TB infection (LTBI) who are free from TB disease.

A person with TB may be unemployed and financially dependent on someone else, or be employed, and responsible for the well-being of others. Other dependencies may be associated with age, such as for children and elderly persons, or to physical, emotional, social, or mental disadvantages. This status, combined with the specific socio-financial circumstances of the person with TB, and of the nature of dependencies involved, has considerable relevance from the point of view of stigma and discrimination.

Individuals with a Direct Relationship with the Person with TB

Individuals who have a direct relationship

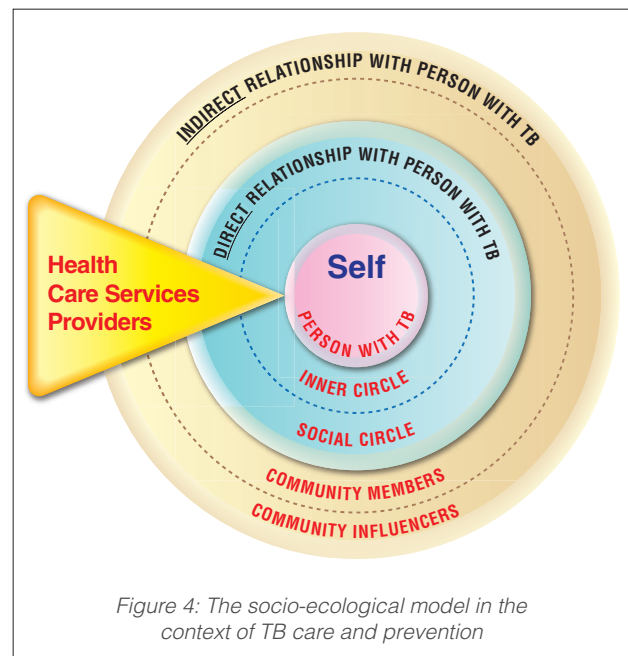


Figure 4: The socio-ecological model in the context of TB care and prevention

with the person with TB are divided into two groups: those in the Inner Circle and those in the Social Circle of the person with TB.

Inner Circle

The Inner Circle includes people who are close to the person with TB, for example, immediate family members and close friends. People in this group spend a lot of time with the person with TB, often sharing an emotional bond with her/him. They are substantially invested in the person with TB.

Inner Circle members may or may not share a household with the person with TB. Immediate family members often do, with the older members of the family at home, and the younger children going to school. Unrelated members who share the household could be friends or co-workers, or migrant men or women working in cities. They may share their bedding, clothes, and even towels; eat together, sharing their food and utensils; clean and wash their clothes and utensils together; and so forth. They often share toilets and bathrooms as well.

Social Circle

The Social Circle comprises of people who frequently interact with the person with TB, and/or with this person's Inner Circle, but have

18. The Social-Ecological Model: A Framework for Prevention. <http://www.cdc.gov/violenceprevention/overview/social-ecologicalmodel.html>

no close emotional ties to them. The Social Circle includes people in the neighborhood, workplace colleagues, classmates, and extended family members.

People in the Social Circle meet frequently in corridors, doorways, lanes, shops, schools/colleges, offices, and at other places like water collection points; they may leave together for work; their spouses spend time in the afternoon chatting; and their children play indoors and outdoors with each other. They celebrate traditional festivals together and visit each other's houses on special occasions, borrow appliances or food, or chat informally. As workplace colleagues, they may have been working with the person with TB for years. They meet for tea breaks, and have and share their lunch. At these break times, they sit together and chat about work and about their personal lives. They are also extended family members, who occasionally visit each other's houses for special occasions.

Individuals with an Indirect Relationship with the Person with TB

Others have an indirect relationship with the person with TB, and/or their inner circle. They may or may not be aware of anyone with TB, even if they are actually interacting with such a person. They include community members and community influencers.

Community Members

This group includes people who are from the same community as the person with TB; they may share common interests based on age, language, religion, caste, class, ethnicity, culture, values, socioeconomic status, occupation, hobbies, and so forth. Their interactions with persons with TB are usually infrequent, or nil.

Community Influencers

Community influencers are prominent figures within the communities or sub-communities with which the person with TB identifies. They may also be from other influential communities, for example, a global community with shared interests. Community influencers are

generally trusted and their opinions valued by community members, including by persons with TB, and often, by their Inner Circle.

Community influencers may be part of various non-health institutions, organizations, and associations. These can be government and non-government, and can be in the fields of management, education, finance, industry, religion, and others. These may be public agencies, civil society organizations, donor agencies, implementing partners, community and faith-based organizations, and educational institutions.

Health Care Service Providers and Health Service Influencers

In the context of the adapted socio-ecological model of influence for TB-associated stigma, health providers and institutions are segregated into a cross-cutting group called health care service providers. This group comprises of people from a wide spectrum of health-related services, facilities, associations, and institutions. They include formal and informal health care service providers – doctors, nurses, clinic assistants, allied medical service providers such as pharmacists/chemists and laboratory staff, and frontline health care workers. This also includes medical institutions, health professional associations, pharmacies and medical retailers, health planners, and health experts, working within public and private sectors. The level of influence of members of this group on persons with or affected by TB is high, but varies by type and reputation.

Ecosystem

The environment is the overarching ecosystem, with its laws, policies, guidelines, and social norms that have a direct or indirect effect on the person with TB. The environment includes political and administrative governance, and the government's level of commitment, and investment, to TB elimination. These are determined at local, state, national, and global levels. The environment also includes the overall impact of formal or informal media on information and education.

Section 5: Strategic Interventions

This strategy document gives broad recommendations for interventions aimed at influencing or benefiting different target audiences in different settings.

- The interventions approaches are grouped under 3 buckets: **advocacy, communication, and community engagement.**
- The above interventions may be implemented in 3 location categories: **community, workplaces, and health care facilities.**
- The target audiences are drawn from the Socio-ecological Model of Influence described in the previous section of this document: **persons with TB, inner circle, social circle, community members, health care service providers, and influencers** (in communities, work places and health care delivery).
- The interventions may impact primarily during the **diagnosis, treatment, or post-treatment** phases in the care cascade, or may be cross-cutting.

NTEP state, union territory, district and local government program managers, and managements of NTEP's partner organizations, are expected to be cognizant of the effects of stigma at each stage in the continuum of TB care. Interventions to prevent and reduce stigma and discrimination should be planned and activated accordingly.

Intervention Approaches – Advocacy, Communication, and Community Engagement

To end TB related stigma, interventions are required to negate its drivers and facilitators listed in Chapter 2. Doing so would result in the following favorable conditions:

- Removal of the reasons for, and drivers of, TB related stigma.
- Positive changes in the cultural, social and gender-related norms, with supporting health policies and legal frameworks that prevent and end stigma.
- Mitigation of the harm experienced by persons living with or affected by TB, and negation of the stigmatizing attitudes and discriminatory behaviors that compromise the health and well being of affected populations through effectively planned and measured interventions.
- Based on available evidence, this document suggests **advocacy** interventions involving designing (or changing) and implementing new policies and guidelines. This document also suggests **communication** interventions that provide information, improve awareness, promote review of behavioral norms, and influence intent and positive behaviors. Finally, it suggests interventions involving **engagement of communities**, to collaborate to prevent, mitigate, and end the undesired impact of stigma on TB care outcomes.

Implementation Location Categories: Community, Workplaces, and Health Care Facilities.

The following three subsections address ending stigma in different settings. They list possible manifestations of stigma and discrimination specific to these settings, identify desired results in terms of what would be achieved when there is an end to TB related stigma, and suggests broad interventions under the 3 approaches mentioned above: advocacy, communication, and community engagement.

- Section 5A looks at ending TB related stigma through **interventions in the community**. It covers approaches taken at national, state and local levels, targeting people in each of the rings of the socio-ecological model of influence.
- Section 5B looks at ending TB related stigma through **interventions at workplaces**, both formal and informal. This is a niche, but important space that witnesses stigma and discrimination against persons affected by TB.
- Section 5C looks at ending TB related stigma through **interventions in health care facilities**. Health care facilities and health service providers can be pivotal in changing the way persons affected by TB are treated, and in helping to build their defenses against stigma and discrimination.

Cross Cutting Recommendations to End TB Related Stigma

Policy & Legal interventions

- Instill, among stakeholders a thorough understanding of laws and policies specific to the country and to the concerned State or Union Territory, for ensuring the inclusion of appropriate structural interventions to

support the elimination of TB related stigma and discrimination.

- Pass an anti-stigma bill in parliament (this may not necessarily be limited to TB care).
- The Government of India issues a rights-based policy against stigma and discrimination, applicable to all Indians. Policies and action plans to end stigma and discrimination, specific to States or Union Territories, Districts, and to local needs (in communities, workplaces, health care delivery) are also developed.
- Provide social security for persons with TB and for their families, at least while on treatment.

Programmatic interventions

- Improve availability, access, and affordability to diagnostic services and state of the art diagnostic tests, ensuring that all persons with presumptive TB can get high quality tests, including point of care and more advanced tests if and when needed, with no delay.
- Decentralize voluntary screening and establish specimen collection and transportation to ensure better access to TB testing.
- Enable immediate or timely redressal of grievances faced by persons with TB and their inner circle while accessing TB care services.
- Establish a national-level monitoring system to capture stigma, discrimination and rights violations experienced by persons with TB and their inner circle in health care and other key settings, and of actions taken towards their redressal. The monitoring system should engage persons affected by TB among other experts.

Research

- Encourage research on social determinants of health, on effects of stigma on treatment

delays and outcomes, and on solutions for reducing stigma through improved service delivery.

Capacity building of Survivor Communities

- Empower key populations, women, girls and other vulnerable populations with knowledge of their legal rights – and, where appropriate, their responsibilities under

the law – and how they can access legal support and redress.

- Enable networks of TB survivors to monitor and report incidents of stigma and discrimination, advocate with relevant stakeholders to mitigate its impacts and to work with relevant stakeholders to collectively build stigma free environments.

Section 5A: Ending TB Related Stigma through Interventions in the Community

This section covers interventions that address stigma in or for community settings. It includes advocacy, communication, and community engagement to reach persons with presumed TB and those with TB disease, and persons who have direct or indirect relationships with TB affected people.

Some manifestations of stigma in the community

- Persons with TB perceive or anticipate stigma and hide the disease.
- If self-perpetuated, stigma may limit a TB affected person's access to care and support.
- Segregation, neglect, and isolation of a person with TB by her/his inner circle within the household; even expulsion from home.
- Inner circle blaming a person with TB for bringing bad luck and misfortune.
- Inner circle separating mothers from children, even preventing them from breastfeeding infants.

- Self or Inner circle delaying care seeking, or a person with TB seeking care from unqualified practitioners to avoid stigma.
- Social circle exhibiting stigmatizing attitudes and behaviors, resulting in a person with TB and her/his inner circle being boycotted or isolated from the community, or a residence identified as 'the house with TB'.
- Social circle blaming a person with TB and her/his inner circle for getting infected.
- Social circle expelling a person with TB and/or her/his family from their home, community, school, etc. and refusal to share public places and resources such as water, children's play areas, community centers, etc.
- Social circle remaining prejudiced, even after the person with TB is cured, and not resuming social or work connections, thus affecting the affected family socially, mentally, emotionally and economically.

Desired Results of ending stigma associated with TB through community interventions

- General population is legally protected against stigma and discrimination due to TB, through enactment of laws and policies, which are adequately strengthened so as to be effective.
- General population is aware that TB is curable, and that its transmission may be prevented.
- Persons with presumed TB seek early health care without fear of stigma or discrimination.
- Persons with presumed TB, those with TB disease, and those in their inner circles, receive standardized, high quality, care and support, and are free to live with TB, without fear of stigma and discrimination.
- Persons with TB disclose their TB status to their inner circle, so that they may be supported through the treatment, and also to their close contacts, so that the latter may be screened and tested.
- Persons with TB comply with, and complete, prescribed treatment regimens, and follow infection control practices.
- Persons cured of TB are not stigmatized or discriminated against in any forum.
- TB patients are cared at home without fear and prejudice about the disease.
- Household/family contacts of persons with TB maintain normal family and social interactions without fear of stigma or discrimination.

Strategic Community Level Interventions for Specific Target Audiences

Summary of Key Community Level Interventions

- Spread messages to normalize TB among all target audiences.
- Encourage communities to promote understanding, empathy, and support, to persons with TB and to members of their inner circle.
- Disseminate messages that help prevent TB, reduce its spread, and encourage early diagnosis and treatment compliance and completion.
- Improve awareness about the symptoms of TB. Inform people on where to seek health care in their vicinity, on what to expect from health care providers, and disseminate messages to reduce fear and stigma.
- Where possible, use positive deviants from a target audience to spread messages that influence behavior change, or foster desired behaviors, among others of the same group. TB survivors can also play an important role in influencing people, especially those with TB and members of their inner circle.
- Strategically engage influencers from political, business/industry, social, and health care arenas to influence communities and people affected by TB, using ways that are mutually beneficial to all concerned.
- Invest in 360-degree communication campaigns on stigma prevention and elimination, effectively and efficiently balancing the use of mass-media, mid-media, outreach (inter-personal communication), and digital (social) media; the campaigns focus on offering solutions to problems faced by the TB affected persons.
- Create treatment support groups locally, to ensure that issues concerning persons with TB and their inner circle are heard and addressed; these support groups include and are preferably facilitated by empowered TB affected persons, or survivors.

Advocacy

Community influencers

- Develop policies and action plans to end stigma and discrimination, specific to states and districts, and to local needs (in communities, workplaces, health care delivery).
- Plan conversations on TB, especially on its impact on society and on benefits of TB elimination, in political and media forums, in messages by political leaders, celebrities, journalists, etc.
- Provide opportunities for corporate sector stakeholders to develop a common purpose to eliminate TB, including ending stigma and discrimination.
- Provide social security for persons with TB and their families, at least while on treatment.
- Enable immediate/timely redressal of grievances faced by persons with TB and their inner circle while accessing TB care services.
- Identify, educate/train, and create a federation of TB-affected persons (people who have had TB, or who have been major stakeholders in the care of a person with TB) to (a) amplify the needs of people affected by TB, (b) offer solutions to improve NTEP services for affected people, and (c) advocate for improvements in access to quality TB care services.

Communication

Community influencers

- Spread the message “anyone can get TB”, through amplification of personal TB-related experiences of political leaders, celebrities, and other community leaders, at appropriate levels (local, state, national, other).

- Disseminate messages that encourage community influencers to reassure persons with TB and their inner circle that they will be supported in their struggle to overcome barriers to accessing quality TB care services.

Community members

- Disseminate messages to normalize TB: such as “anyone can get TB”, “TB is curable”, “risk of infection reduces when a person with TB starts treatment”, “TB does not spread genetically, or through touching or hugging a person with TB, through associating with their inner circle, or through sharing of food, utensils or clothes”, etc.
- Disseminate messages that help reduce the spread of TB in the community, by promoting early screening and testing among persons with TB symptoms, and on the importance of adopting cough hygiene, and including normalizing the use of masks when needed.
- Disseminate messages that help prevent TB, or encourage early and effective diagnosis, and reduce the burden of TB in the community through improved awareness on importance of nutrition, cessation of smoking and alcohol consumption, early testing for, and effective management of, diabetes, HIV, etc.
- Disseminate messages that promote understanding, empathy, and support, towards persons with TB and their inner circle.
- Disseminate messages that encourage contacts of persons with TB, especially children and other high-risk contacts, to seek screening and testing, and accept preventive treatments if needed.
- Address through positive messaging, identified individual incidents of stigmatizing attitudes or discriminatory behavior among the social circle of persons with TB.

Social circle

- Disseminate messages through positive deviants from the social circle, influencing change in behavior norms, but acknowledging importance of treatment adherence by persons with TB.
- Disseminate messages that promote understanding, empathy, and support, towards persons with TB and their inner circle.

Inner circle

- Improve awareness about the symptoms of TB, and disseminate messages to reduce fear and stigma: messages such as, “TB is curable”, or “TB can be easily defeated, especially if diagnosed and treated early”, etc.
- Address the genuine fear of the infection, especially among those living in the same household.
- Disseminate messages informing the inner circle on TB symptoms, and on where to seek health care in their vicinity.
- Disseminate messages informing the inner circle of what to expect from doctors and other health care providers, e.g., about CB-NAAT testing when a person with TB is presenting with symptoms. Such information can trigger reasonable demands of service providers, and of health systems.
- Disseminate strategically crafted messages on how, and to whom, to reveal a person’s TB status, thus optimizing support without increasing the risk of being stigmatized.
- Disseminate messages on the importance of treatment adherence, and on how inner circle members can support persons with TB in completing treatment.
- Improve awareness about TB and its treatment: duration, medicines, and their common side effects, etc., enabling persons affected by TB to become ‘TB literate’.

- Provide communication through positive deviants from the inner circle, influencing change in behavior norms, but including importance of treatment adherence.
- Disseminate messages instilling confidence among members of the inner circle to seek medical or social support for their person with TB, or for themselves.
- Disseminate messages promoting understanding, empathy, and support, towards persons with TB.
- Disseminate messages that encourage contacts of persons with TB, especially children and other high-risk contacts, to seek screening and testing, and accept preventive treatments if needed.

Persons with TB (or persons with presumed TB)

- Improve awareness about the symptoms of TB, and disseminate messages to reduce fear and stigma: messages such as, “TB is curable”, or “TB can be easily defeated, especially if diagnosed and treated early”, etc.
- Disseminate messages informing persons with TB of symptoms, and on where to seek health care in their vicinity.
- Disseminate messages informing persons with TB of what to expect from doctors and other health care providers, e.g., about CB-NAAT testing when a person with TB is presenting with symptoms. Such information can trigger reasonable demands of service providers, and of health systems.
- Disseminate strategically crafted messages on how, and to whom, to reveal one’s TB status, thus optimizing support without increasing the risk of being stigmatized.
- Disseminate messages to normalize TB: such as “anyone can get TB”, “TB is curable”, “risk of infection reduces when a person with TB starts treatment”, “TB does

not spread genetically, or through touching or hugging a person with TB, or through sharing of food, utensils or clothes”, etc.

- Disseminate messages on the importance of treatment adherence, and to identify if self- or anticipated stigma in the person with TB is interfering with adherence.
- Improve awareness about TB and its treatment: duration, medicines, and their common side effects, etc., enabling persons with TB to become ‘TB literate’.
- Improve awareness on the importance of reporting any persistent side effects to the concerned medical personnel, and on seeking timely care for these.
- Disseminate messages delivered by empowered peers (people who have, or had, TB).
- Disseminate messages boosting self-confidence and the belief that TB will be cured, including messages that prevent (or dispel) fear of losing employment, friendships, relationships, of having to drop out of school/college etc.; and of fear that promotes self-stigma and perceived stigma.
- Disseminate messages to encourage (a) good nutrition, (b) cessation of smoking, (c) cessation of alcohol consumption, (d) testing for diabetes and HIV, etc.
- Disseminate messages that encourage cough hygiene in a positive way, and encourages the use of masks when the person with TB is potentially infectious.

Community Engagement

Community influencers

- Use celebrity voices at community level events to support local, district, state, and/or national level movements to prevent and eliminate TB: these voices call for improved quality of care as well as improved access and availability of TB diagnostic and treatment services across public and

private sectors.

- Invite community influencers to treatment support groups, to seek understanding, and to extend support where willing and possible.
- Use relevant experiences of persons with TB, members of their inner and social circles, of health care providers, and other stories to help spread positive messages that encourage early health seeking and treatment adherence, and prevent or end stigma and discrimination.
- Use TB survivors as ‘patient-advocates’, federated at district, state and national levels, to provide honest feedback on quality of care experienced by persons with, and affected by, TB, and offer solutions to problems/challenges and gaps in TB care delivery.

Community members

- Identify positive deviants among community members, addressing stigma prevention and reduction, and amplify their positivity through community events, till positive behaviors towards persons with TB and their inner circle become the norm rather than the exception.
- Conduct awareness drives during political rallies, socio-cultural community events, melas, and festivals, and as standalone TB events, including during active case finding campaigns.
- Amplify TB issues through TV, radio and print media, through first-hand stories of persons with TB, their inner circle, and of health care providers and community frontline workers, with a focus on offering solutions to problems faced by the affected persons.
- Invest in 360-degree TB-ACSM campaigns targeting stigma prevention and elimination, using mass-media, mid-media, outreach (inter-personal communication), and digital (social) media.

- Sensitize community members to TB through empowered ‘patient-advocates’.
- Communities are encouraged to ‘adopt’ persons with TB and their families by providing physical, medical, emotional, and/or financial support, thus ensuring a stigma-free pathway to full recovery.
- Communities engage willing persons with TB, post treatment completion, to support NTEP efforts through different means; such as by providing patient support locally, and by becoming patient advocates at local, district, state and/or national levels, etc.

Social circle

- Members of the social circle of persons with TB are invited to treatment support groups, to seek understanding, and to extend support where willing and possible.

Inner circle and persons with TB

- Create treatment support groups locally, to ensure that issues concerning persons with TB and their inner circle are heard and addressed; these support groups include and are preferably facilitated by empowered TB affected persons.

Section 5B: Ending TB Related Stigma through Interventions at Workplaces

This section covers interventions that address stigma by engaging with employers and employees in both formal and informal work settings. This is a niche, but important, space that witnesses much stigma and discrimination against persons affected by TB. Addressing this will contribute to the prevention of financial crises among TB affected persons and their families, and to improving productivity through retention of trained and skilled personnel.

Workplace settings comprise all settings in which people work. These include formal wage employments, and informal employments, such as agricultural labor, daily skilled/unskilled labor, street vending, hired domestic work, etc. The formal sector includes employment in private and public sectors, and includes micro- and small institutions and large-scale establishments. People in workplace settings

include employers and co-workers who may interact with the persons with TB, but may not necessarily share any emotional ties with them. As workplace colleagues, they may have been working with the person with TB for years. They meet for tea breaks, and have and share their lunch together. During these breaks, they sit together and chat about work, and about their personal lives.

Being able to work has immeasurable implications on the livelihood and well-being of a person with TB, their family and their community. Many employees are migrants at their place of work and may be dependent on the employer, and on co-workers, for health care needs. For the convenience of workers and managements, NTEP TB care services can be provided at many workplaces. Following these guidelines, and developing locally relevant action plans, ensures that

persons with or affected by TB receive the best TB care possible, and in a manner that is beneficial for workers, workplace managers, and business owners.

Some manifestations of stigma in workplaces

- Co-workers are afraid to mingle with persons with TB, stop interactions, and refuse to be with them.
- Persons with TB are directly or indirectly told to not wear masks, or not take medicines at workplaces, and to hide their TB status.
- Persons with TB are not provided with necessary leave to access health care.
- Persons with TB are denied work opportunities, or promotion, or are pressured to resign, or are terminated from employment.
- Long-term stigma and discrimination may prejudice against individuals, or family members of persons who have TB, often even after their successful completion of treatment.

Desired Results of ending stigma associated with TB through workplace interventions

- All employees and workers (whether in formal or informal workplaces) are legally protected against stigma and discrimination due to TB, and owners and management of workplaces endorse a policy that includes having a universally non-stigmatizing and non-discriminatory work environment.
- All employees and workers are aware that TB is curable, and that its transmission may be prevented.
- Persons with TB, and those who had the disease in the past, can seek or continue employment without fear of stigma or discrimination.

- Employees and workers with TB disclose their TB status to close contacts, so that the latter may be screened and tested.
- Persons with TB feel confident to seek and access health care, and are enabled to follow TB management protocols, including infection control measures, without fear of stigma or discrimination.
- There is reasonable accommodation in workplaces, with greater understanding about issues faced due to TB and offer of job security to TB affected persons, modification in duties to be performed in terms of waiving certain activities that may create exertion, breaks to attend to specific health needs, and in response to requests by the employee for accommodating TB related disabilities.

Strategic Workplace Level Interventions for Specific Target Audiences

Summary of Key Workplace Level Interventions

- In workplaces where NTEP services are not available, carry out advocacy with workplace managers to provide TB services under the program, including screening, testing, treatment, and post diagnosis care and support.
- Advocate for a workplace policy against stigma and discrimination, with specific recommendations and action, including legal measures, against discriminatory practices by employers or co-workers, including during the hiring process and period of employment.
- Sensitize employers about the impact of TB and TB stigma on workers' productivity and their unique position to support their employees who are affected by TB through early identification, and initiation and completion of treatment.

- Encourage TB survivors and TB survivors' networks to share the perspectives of persons with TB, and to advocate for a TB and TB related stigma free work environment.
- Improve awareness about TB among business owners/proprietors, and management personnel.
- Spread message that normalize TB through amplification of personal TB-related experiences of political leaders, celebrities, and other business community leaders.
- Disseminate messages that prevent TB, its transmission from one person to another, and help contacts of persons with TB to reach out for screening, testing, and where needed, for treatment.
- Disseminate messages that promote understanding, empathy, and support, towards co-workers with TB and their family members.
- Disseminate messages through positive deviants from among co-workers, influencing changes in behavior norms, or through empowered TB survivors.
- Establish treatment support groups, preferably facilitated by TB survivors, to encouraging sharing of experiences and redressal of issues pertaining to people with TB.

Advocacy

Workplace community influencers

- Workplaces establish policies that prevent and address stigma and discrimination, based on legal/statutory and technical guidelines existing in the country.
 - > Develop protective workplace policies by engaging lawmakers and other decision-makers.
 - > Engage with industry and business federations to self-assess their work

place policies and practices in terms of TB related stigma and discrimination, formulating changes if needed.

- > Engage with employee collectives/unions/associations to support the development and implementation of such policies across the formal sector.
- > Engage with industry and formal business bodies to identify and promote positive deviants within both employers and employees that promote TB control efforts and measures for ending TB related stigma.
- Plan conversations on TB, especially on its impact on workers morale and productivity, and on benefits of TB elimination in the workplace.
- Corporate sector stakeholders and employee unions develop a common purpose to eliminate TB, including ending stigma and discrimination.
- Where feasible, workplaces provide for social security for workers with TB and their families, at least while a worker is unable to work.
- Enable immediate/timely redressal of grievances faced by workers with TB.
- Ensure to provide for reasonable accommodation in work place.

Communication

Workplace community influencers (they include government ministry officials, industry owners, proprietors, management personnel, employer/employee collectives, insurance agencies, etc.)

- Improve awareness about TB among owners, proprietors, and management personnel.
- Spread the message “anyone can get TB”, through amplification of personal TB-related experiences of political leaders,

celebrities, and other community leaders, at appropriate levels (local, state, national, other).

- Disseminate messages that encourage owners, proprietors, and management personnel at workplaces that inform workers of intolerance to stigma and discrimination at the workplace, that in turn reassures workers with TB and their families that their jobs will remain reasonably secure.

Co-workers of people who have TB

- Disseminate messages to normalize TB: such as “anyone can get TB”, “TB is curable”, “risk of infection reduces when a person with TB starts treatment”, “TB does not spread genetically, or through touching or hugging a person with TB, through associating with their inner circle, or through sharing of food, utensils or clothes”, etc.
- Disseminate messages that help reduce the spread of TB in the workplace, by promoting early screening and testing among workers with TB symptoms, and on the importance of adopting cough hygiene, and including normalizing the use of masks when needed.
- Disseminate messages that help prevent TB, or encourage early and effective diagnosis, and reduce the burden of TB in the workplace through improved awareness on importance of nutrition, cessation of smoking and alcohol consumption, early testing for, and effective management of, diabetes, HIV, etc.
- Disseminate messages that promote understanding, empathy, and support, towards co-workers with TB and their family members.
- Disseminate messages that encourage contacts of workers with TB to seek screening and testing, and accept preventive treatments, if needed.

- Address through positive messaging, identified individual incidents of stigmatizing attitudes or discriminatory behavior among the co-workers of persons with TB.
- Disseminate messages through positive deviants from among co-workers, influencing change in behavior norms, but acknowledging the importance of treatment adherence by workers with TB.

Persons with TB at workplaces (or persons with presumed TB)

- Improve awareness about the symptoms of TB, and disseminate messages to reduce fear and stigma: messages such as, “TB is curable”, or “TB can be easily defeated, especially if diagnosed and treated early”, etc. Workers should also be aware of where to go if they have/recognize TB symptoms, and on what to expect from health care providers when they do. Also improve awareness about TB and its treatment: duration, medicines, and their common side effects, etc., enabling persons with TB to become ‘TB literate’.
- Disseminate messages to normalize TB: such as “anyone can get TB”, “TB is curable”, “risk of infection reduces when a person with TB starts treatment”, “TB does not spread genetically, or through touching or hugging a person with TB, or through sharing of food, utensils or clothes”, etc.
- Disseminate strategically crafted messages on how, and to whom, to reveal one’s TB status, thus optimizing support without increasing the risk of being stigmatized.
- Disseminate messages on the importance of treatment adherence, and to identify if self- or anticipated stigma in the person with TB is interfering with adherence.
- Improve awareness on the importance of reporting any persistent side effects to the concerned medical personnel, and on seeking timely care for these.

- Disseminate messages delivered by empowered peers (people who have, or had, TB).
- Disseminate messages boosting self-confidence and the belief that TB will be cured, including messages that prevents (or dispels) fear of losing employment, friendships, relationships, of having to drop out of work, etc.; and of fear, that promotes self-stigma and perceived stigma.
- Disseminate messages to encourage (a) good nutrition, (b) cessation of smoking, (c) cessation of alcohol consumption, (d) testing for diabetes and HIV, etc.
- Disseminate messages that encourage cough hygiene in a positive way, and encourages the use of masks when the person with TB is potentially infectious.
- Owners, proprietors, and management personnel uses relevant experiences and stories of workers with TB, members of their families, and of health care providers, to help spread positive messages that encourage early health seeking and treatment adherence, and prevent or end stigma and discrimination.

Co-workers of people who have TB

- Identify positive deviants among coworkers to address stigma prevention and reduction, and to amplify their positivity until positive behaviors towards workers with TB become the norm rather than the exception.
- Workers' communities are encouraged to 'adopt' co-workers with TB and their families by providing physical, medical, emotional, and/or financial support, thus ensuring a stigma-free pathway to full recovery.
- Where willing and possible, co-workers are invited to treatment support groups, to seek understanding, and to extend support to workers with TB.

Persons with TB at workplaces (or persons with presumed TB)

- Create treatment support groups at large workplaces, or link TB affected workers to other such groups, to ensure that issues concerning persons with TB are heard and addressed.

Community Engagement

Workplace community influencers

- Use industry leaders and influencers to support movements to prevent, manage, and eliminate TB from workplaces: these voices call for improved quality of care as well as improved access and availability of TB diagnostic and treatment services.
- Owners, proprietors, and management personnel are invited to treatment support groups, to seek understanding, and to extend support where willing and possible.

Section 5C: Ending TB Related Stigma through Interventions at Health Care Facilities

The health fraternity has a large spectrum, and as described above in this document, includes formal and informal providers, clinical and supporting health service providers, medical institutions, health professional associations, pharmacies and medical retailers, health planners, and health experts, all working within public and private environments. This section targets all the above, but mainly covers interventions that address stigma by engaging with doctors and other frontline health care staff, and managements of health care facilities.

Health care providers are in a unique position to influence people with TB, their inner circle, and indeed the wider community and community influencers on matters concerning stigma and discrimination. The level of influence of members of this group on persons with or affected by TB is very high, but varies by type and reputation. As providers of health care services, those having direct contact tend to influence how their patients and their attendants feel. Their language and behaviors therefore need to be positive, non-stigmatizing and non-discriminatory. Their opinions and advice also go a long way in how their patients and attendants deal with, and/or propagate stigma.

Some manifestations of stigma in health care facilities

Stigma manifestations and discrimination in health care settings are usually short

term and may not be repeated, especially when in hospital settings. However, stigma or discrimination experienced or perceived by persons with TB or members of their inner circle have huge impact on affected individuals, challenging and even disabling them from accessing quality health care. This may in turn impact treatment outcomes. Manifestations of stigma may include, but are not limited to:

- Inadvertently hiding the reality of TB behind euphemisms such as 'Koch's disease', giving the impression that 'TB' or 'tuberculosis' are terms to be avoided.
- Not giving adequate information about TB, and discouraging information seeking by patients or their attendants.
- Keeping a physical distance from the TB patients, and not touching patients by way of physical examination, or communicating through overall body language that the patient is to be avoided.
- Wearing personal protective equipment such as shields, masks, and/or gloves, only with persons with TB, but not when dealing with other patients.
- Denying in-patient care for TB when needed.
- Persons affected by TB, being sensitive to stigma and discrimination in the face of the disease, have also attributed generalized unfriendly behaviors of health care personnel to be manifestations of stigma.

Desired Results of ending stigma associated with TB through health care facility interventions

- Health care providers understand the impact their words, behaviors and actions have on patients and their families, and are sensitive to the adverse impact of stigma associated with TB in the lives of their patients, and in the way their patients comply with TB management protocols.
- Health care providers acknowledge the importance of all aspects of TB management, not just through medical and public health actions, but also through psycho-social support of persons with, and those affected by, TB.
- Health care providers educate their patients and their inner circle about TB, and counsel them, at each stage of its management. They promote screening and testing of contacts. They also encourage and support TB patients and their inner circle to fully adhere to treatment regimens.
- Health care providers educate their patients and their inner circle on ways to prevent TB transmission, and to follow infection control practices, including cough etiquette and use of masks.
- Health care providers evaluate their patients holistically, ascertaining risks to treatment compliance that are beyond medical realm, and including social, psychological and financial risks. They are empowered to advice their patients on prevention of stigma and discrimination – perpetuated by others such as members of the inner circle, social circle or community of the person with TB, or of self-perpetuated stigma.
- Health care providers encourage persons with TB to disclose their TB status as needed, so as to be able to access standard, high quality, care and support services.

- Health care providers use non-stigmatizing language and are sensitive to their patient's emotional and social needs.

Strategic Health Care Facility Level Interventions for Specific Target Audiences

Summary of Key Health Care Facility Level Interventions

- The rights-based policy against stigma and discrimination issued by the Government of India includes recommendations for health care service providers.
- Standards for stigma-free TB care are included in the Standards for TB Care in India.
- Include stigma prevention and elimination, and addressing of social issues, in medical education and in health care provider training programs. Awareness of patient rights among health care providers are improved, and stigma is included as a topic in medical conferences.
- Build the capacity of health care providers on use of soft skills, including suitable tone of voice, counseling techniques, avoidance of stigmatizing language or use of euphemisms, and encourage health care providers to openly discuss TB with persons with TB and their inner circle.
- Improve mechanisms to protect health care staff from infection, and provide timely post-infection support when needed, thus reducing fear among health personnel.
- Provide communication aids to health providers, supporting dialogue with persons affected by TB.
- Encourage communities of health care providers and associations of health care facilities to (a) promote adoption of non-stigmatizing and non-discriminatory language and tone while dealing with people affected by TB, and (b) to engage in conversations on stigma with persons affected by TB to help them deal with, or avoid, stigma and discrimination in various settings.

Advocacy

Health care community influencers

- The rights-based policy against stigma and discrimination issued by the Government of India, applicable to all Indians, includes a distinct section with recommendations for health care service providers.
- Include standards for stigma-free TB care in the Standards for TB Care in India.
- Include stigma prevention and elimination and addressing of social issues, in medical education, in health care provider training programs; public and private, in NTEP and donor-supported TB interventions. When addressed by health care providers, this will help prevent self-stigma among persons with TB, and build their confidence to deal with stigmatizing behaviors of others.
- Advocate for capacity building of health care providers on use of soft skills, including suitable tone of voice, counseling techniques, avoidance of stigmatizing language or use of euphemisms, and encourage health care providers to openly discuss TB with persons with TB and their inner circle.
- Enhance the quality of public and private TB services to address social determinants of TB, and include indicators to measure improvements in quality of care, engaging persons affected by TB in evaluations of health services.
- Educate medical personnel involved in provision of TB care on shifting behavior norms and attitudes, and on use of non-stigmatizing language at all levels of health/ medical education, service delivery, and program management.
- Ensure adoption of standards by all health care service providers involved in the continuum of TB care, thus reducing opportunities for the creation and fomentation of stigma that result from delays and poor quality of care.
- Improve mechanisms to protect health care staff from infection, and provide timely post-infection support when needed, thus reducing fear among health personnel.
- Engage and utilize social scientists, and social and behavior change communication experts, to build the capacity of health care service providers, especially those engaging with PwT and their IC, to deal with the social aspects of TB management.
- Improve awareness of patient rights among health care providers – of all type and sector – ensuring that patients too have the right to be treated with dignity, respect, and equity.
- Improve availability, access, and affordability to diagnostic services and state of the art diagnostic tests, ensuring that all persons with presumptive TB can get high quality tests, including point of care and more advanced (if needed) tests, with no delay.
- Decentralize screening and establish specimen collection and transportation for better access to TB testing, for those who prefer these services.
- Engage leaders among health care providers, and advocate for the adoption of standards for TB care by all care providers, providing user-friendly services, especially to those in the private sector to ensure that the standards are adopted.
- Engage non-medical staff, including social workers, psychologists, etc., to support management of persons with TB and their inner circle, and establish links between TB service providers and professional psychologists and mental health specialists to address serious consequences of stigma and discrimination.

- Establish patient-friendly quality of care across health care delivery systems and facilities.

Communication

Health care community influencers (they include government, ministry officials, public health experts, owners/proprietors/partners of corporate hospitals, directors and other senior officials of medical colleges and other tertiary/secondary hospitals, medical superintendents, hospital board members and their equivalents, Managing Directors/CEOs of pharma and diagnostic companies, office bearers of medical, nursing and other health professional associations, etc.)

- Disseminate messages on how stigma counters good medical practice in TB care, and on what health care providers can do to prevent and remove stigma.
- Include stigma as a topic in medical conferences.
- Provide opportunities for health care service providers to develop a common purpose to end stigma and discrimination among TB affected people.
- Encourage research on social determinants of health, on effects of stigma on treatment delays and outcomes, and on solutions for reducing stigma through service delivery.
- Include social management of TB, and address stigma prevention and elimination, in medical education curricula, and agenda for service provider trainings, workshops, conferences, consultations, etc.
- Disseminate messages to clinicians on the importance of transparency about TB to persons with TB and members of their inner circles, helping to build confidence that TB is not something to be hidden or ashamed of.
- Disseminate messages that promote counseling, addressing social, emotional, psychological, and other issues, at each stage of the diagnostic process, to (a) help prepare persons with presumptive TB and their inner circle to accept any of the possible diagnostic results without feeling ashamed or stigmatized, and (b) help prepare persons diagnosed with TB, and their inner circle, to live with TB, retaining their dignity and self-esteem.
- Disseminate messages that promote education of persons with presumptive or diagnosed TB and their inner circle, by health care providers, at each step of the diagnostic process.
- Provide communication aids to health care providers to support dialogue with persons with presumptive or diagnosed TB and their inner circle; these aids improve awareness among TB affected persons and address confidentiality, fears, and expectations, thus mitigating stigma.
- Disseminate messages to health care providers to encourage persons with TB and members of their inner circle to disclose their TB status to those who need to know (e.g. NTEP, treatment supporter, close contacts, etc.) with reassurance that the information is otherwise kept confidential.
- Disseminate messages to health care providers on how stigma counters good medical practice in TB care, and on what health care providers can do to prevent and mitigate stigma.
- Disseminate messages that trigger empathy and affirmative messages by health care providers throughout the course

Qualified doctors and other medical personnel, including community frontline workers

- Disseminate messages promoting the use of honest and consumer-friendly language that is non-stigmatizing to persons with TB and to members of their inner circles.

of a person's treatment to strengthen persons with TB and members of their inner circle, thus building trust and willingness to be adherence compliant and complete treatment.

Community Engagement

Health care community influencers

- Communities of providers (such as professional associations) ensure that health care providers receive support in acceptable ways to provide patient-friendly TB services. Such support encourages adoption of standards for TB diagnosis, notification, and provision of treatment support, including treatment monitoring and contact evaluation.
- Establish regulatory mechanisms to ensure that all health care providers follow standards for TB care.
- Include social management of TB, and address stigma prevention and elimination, in medical education curricula, and agenda for service provider trainings, workshops, conferences, consultations, etc.
- Communities of providers (such as professional associations) ensure that

health care providers are able to counsel persons with TB and their inner circle on social, emotional and psychological issues at each stage of treatment to improve adherence and help them live with the disease, retaining their dignity and self-esteem.

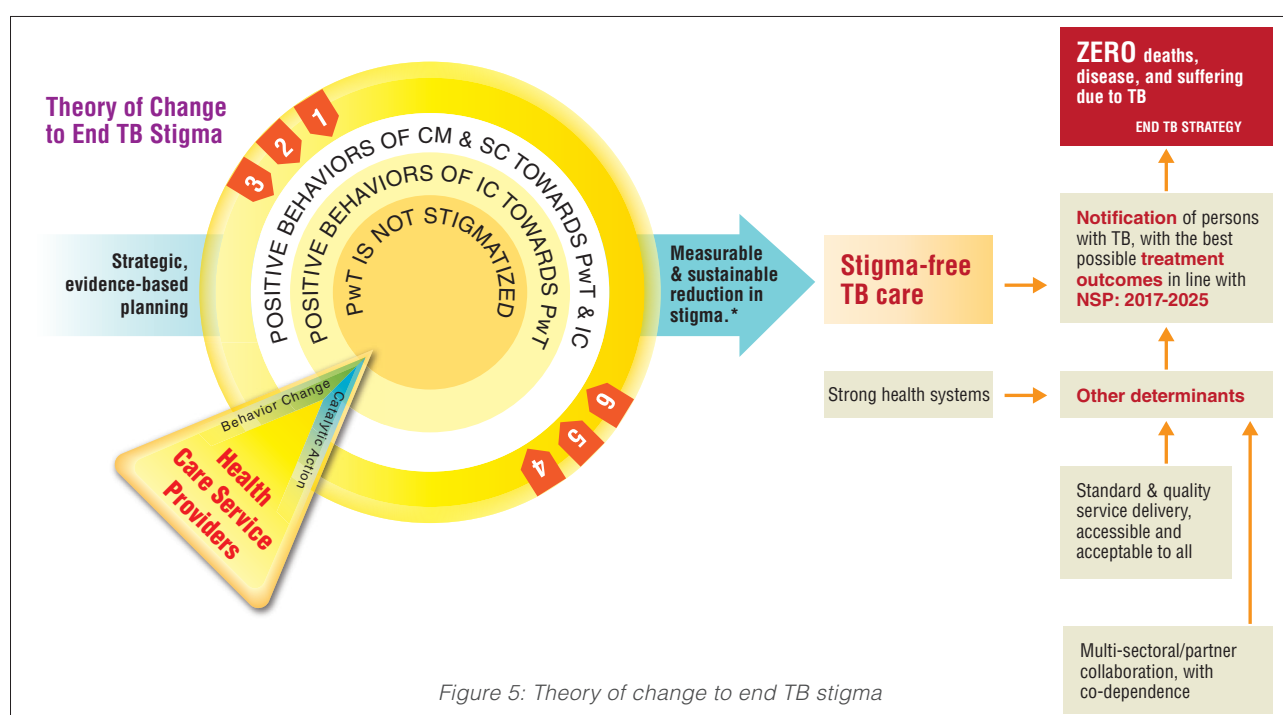
- Communities of providers (such as professional associations) ensure that health care providers continue to address social issues, including identifying and mitigating stigma and discrimination, while evaluating persons post treatment completion.

Qualified doctors and other medical personnel, including community frontline workers

- Health care service providers practice patient- and provider-friendly services in public and private health service delivery, encouraging adoption of standards for TB diagnosis, and mitigating barriers to screening, referral, and testing of persons with presumptive TB, and of diagnosing PwT, in any service sector.

Section 6: Monitoring & Evaluation for the End TB Stigma Strategy

It is important to monitor and evaluate efforts to end TB stigma while implementing the principles and strategic interventions articulated in this end TB stigma strategy document. The following guidelines and indicators will be applied to measure input and responses to implementation, guided by the Theory of Change depicted in Figure 5.



Legend for Catalytic Action by Stakeholders in Ecosystem

1. Rights-based policies, guidelines
2. Equitable funding
3. Implementation & management capacity
4. Technical capacity for advocacy, communications, & community engagement
5. Technical capacity for quality of care in service delivery
6. Effective monitoring, evaluation, & learning

Acronyms

- CM: Community Members
- SC: Social Circle
- IC: Inner Circle
- PwT: Person with TB
- HCP: Health Care Providers

Guidelines for rolling out and measuring impact of the strategy to end TB stigma

- Planning to ensure that all persons with, or affected by, TB, benefit from locally effective, and specific, stigma mitigation plans:
 - > All NTEP stakeholders establish and articulate plans to roll out the strategy to end stigma and discrimination associated with TB;
 - > These plans build on the principles and strategies included in this document, and address identified needs that are specific to local geographies and populations;
 - > Further micro-level planning is carried out and implemented to end, prevent, and mitigate stigma and discrimination among all people with, or affected by, TB.
- Roll out of the end TB stigma strategy, and measuring impact at different levels:
 - > This strategy guides all TB stakeholders and is the input document for the NTEP at the national level;
 - > States and Union Territories will build on the national strategy and develop plans that are State and Union Territory specific. District NTEP officials will develop micro-plans that ensure that all TB affected persons benefit from the strategy, and where needed, have strategies and plans that incorporate locally relevant needs and nuances;
 - > All NTEP partners, irrespective of their funding source, will develop action plans to end TB associated stigma relevant to their scope and scale of work; where pertinent, partners will follow the guideline of having level-specific action plans at national, state and local levels described above.
- All action plans to roll out the strategy to end TB stigma will include an effective, but realist, monitoring and evaluation plan.

Measuring the impact of the strategy to end TB stigma at the national level

WHAT THE STRATEGY EXPECTS	MEASURING ACHIEVEMENTS AGAINST EXPECTATIONS AND INDICATORS
Vision: a stigma-free TB response. Goal: to end stigma and discrimination faced by persons with or affected by TB, through all stages of the continuum of care.	Multicentric quantitative base-line (2021) and end-line (2024) studies evaluating TB associated stigma and discrimination, and impact of rolling out the end TB stigma strategy. TARGET: 75 percent reduction in stigma associated with TB.
Principles: 1. People affected by TB are able to live and access TB services without being judged. 2. People in the social circle of TB-affected persons and members of the community do not fear TB, but are assured that it is a treatable disease, and that their support of persons with TB will result in early and better recovery, and thus prevent its transmission to others. 3. Community influencers contribute to fostering of safe and acceptable environments; their actions promoting positive social behaviors towards people affected by TB. 4. Health care service providers and health influencers adopt standards for TB care and their capacity in using stigma-mitigating soft-skills and language is built.	Qualitative studies carried out at State and Union Territory levels – and where convenient, at district levels – among people affected by TB (persons with TB and people in their inner and social circles), communities, and among health care service providers. The studies are carried every year from 2021 to 2024, to assess: • Prejudices against persons affected by TB, and willingness of persons with TB to access NTEP services without fear; • Fear among the social circle of TB-affected persons and members of the community, and their willingness to support persons with TB; • Community activities promoting positive social behaviors towards people affected by TB; and • Use of improved soft skills and non-stigmatizing language by health care providers caring for persons with TB.
Objectives: 1. Advocate for resource investments to end stigma and discrimination associated with TB. 2. Adopt, build capacity, and implement a cross-cutting and integrated stigma prevention and reduction strategy in all TB care activities, with active participation of TB affected people. 3. Develop and execute a communications strategy, using multiple media and formats, addressing various dimensions of TB-related stigma and discrimination. 4. Design and support the roll out of community-led interventions that mobilize societies to foster non-stigmatizing and non-discriminating behaviors towards persons with or affected by TB.	High-level NATIONAL indicators 1. Resources invested to end stigma and discrimination associated with TB; 2. Adoption and implementation of a stigma prevention and reduction strategy in TB care activities, with active participation of TB affected people; 3. States and partners supported for the development of local strategies and operational guidelines for advocacy, communications, and community engagement, to end TB associated stigma and discrimination. NATIONAL AND SUB-NATIONAL indicators: 4. Advocacy actions undertaken to improve resource allocation and effort to end TB associated stigma and discrimination; segregated by level of action; 5. Communication messages and posts that are aimed at preventing, ending, and mitigating TB associated stigma and discrimination; segregated by route of messaging – mass media, social media, print, out-of-home (posters, hoardings), and other; 6. Community engagement activities that solely or inclusively address TB associated stigma and discrimination; segregated by type of activity, and level. Other OUTPUT indicators reported by States and Union Territories, and monitored at the NATIONAL level: 7. TB affected persons recruited, and sensitized or trained, to support the NTEP's efforts to end stigma and eliminate TB; disaggregated by gender, and level or recruitment and sensitization/training; 8. Sensitization/training modules developed for capacity building in stigma mitigation; disaggregated by target audience, and level; 9. Research activities concerning stigma and discrimination associated with TB, and addressing where in the continuum of care to focus, and on how to act; segregated by type of stakeholder conducting the research, and level.

Annexure 1:

Eliminating Stigmatizing Language

There is a global call to ensure that the TB response is people-centered and rights based. The first step towards this goal has to be an acknowledgement that the language commonly used to speak about TB must evolve. Language influences stigma, beliefs and behaviors, and may determine if a person feels comfortable with being tested or treated. The TB response should shift to more empowering, people-centered, language to help bring TB out of the shadows and encourage people to speak about it.

Context is the critical factor in determining what language is appropriate in certain settings. We must ensure that everyday conversational language is used to communicate with persons affected by TB, as this is empowering rather than isolating. Change will have to begin with how we speak about TB in our homes, in the media, in communities, and in healthcare settings. Here are some examples of more inclusive language that are useful when rendering competent TB care and treatment.

Case – a person seeking or receiving care: A person is not a case but a fellow human being. People seeking or receiving care may find it demeaning if they overhear a health worker describing them as ‘cases’.

Compliance and non-compliance – referring to adherence to prescribed treatment: A term like compliance puts the full responsibility of taking medicines on the person with TB, and the term non-compliance tends to assign blame to the person receiving treatment. In fact, many external factors outside a person's control may be factored in for breaks in treatment.

Defaulter – referring to a person on treatment, who is lost to follow-up: It is incorrect to shift the blame and place it on people with TB by labeling them defaulters. Multiple socio-economic factors may be responsible for a person stopping, or not completing, their treatment.

TB Control– TB Prevention and Care: It is useful to examine the term ‘control’ critically to avoid neglecting the resources of communities and people with TB.

TB suspect– referring to a person to be evaluated for TB; a person with presumed TB: ‘TB suspect’ is sometimes used to define a person who presents with symptoms or signs suggestive of TB. The word, suspect, is accusatory, and should be avoided.

Glossary

Front Line Worker includes community health workers affiliated to public, private & NGO sectors, including treatment supporters.

Health Care Provider includes public & private providers of clinical, para-clinical, & community-based health care services.

Inner Circle includes people who are emotionally, financially or otherwise invested in persons with TB; typically close family members & friends.

Social Circle are people frequently interacting with PwT, and/or IC, but have no close ties to them; typically neighbors, classmates & colleagues.

Treatment Support Group are community groups comprising of PwT, IC, SC, community members and others, to help those with TB.

Person with TB is someone who has drug-sensitive or drug-resistant TB disease of the lungs or of other organs. The term does not include people with LTBI. **A person with presumed TB** is someone who has symptoms or signs of TB and who needs to undergo clinical evaluation, and microbiological investigation.



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Central TB Division

Ministry of Health and Family Welfare,
Nirman Bhavan, New Delhi - 110011
www.tbcindia.gov.in