

# IMPACT REPORT

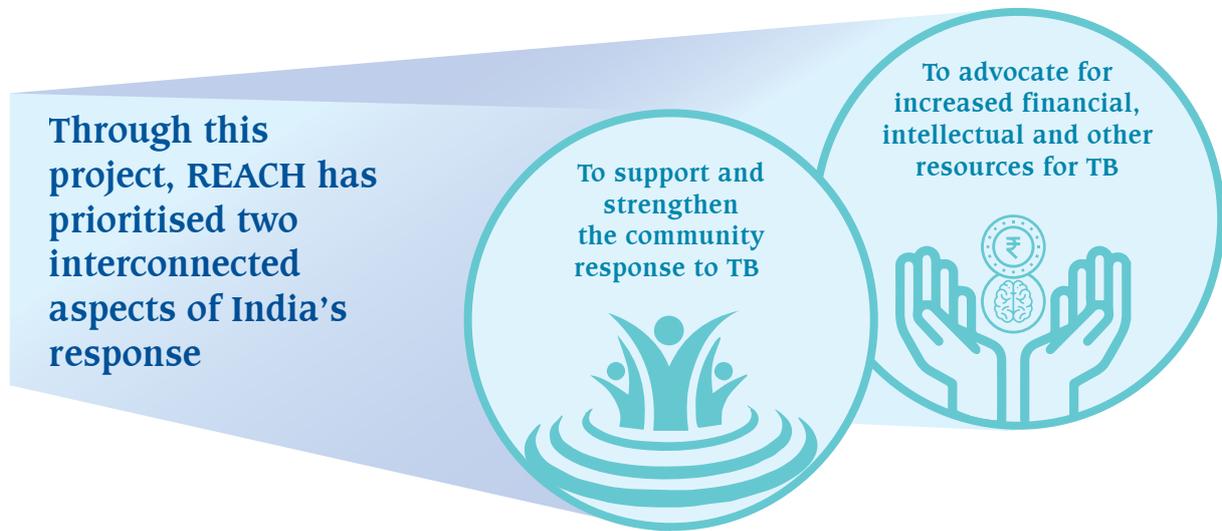


## CALL TO ACTION FOR A TB-FREE ASSAM

**Catalysing a multi-sectoral, community-led  
and collaborative response to TB**



The TB Call to Action Project is a four-year initiative by REACH, supported by the United States Agency for International Development (USAID) and implemented in partnership with the Revised National TB Control Programme (RNTCP) at the national, state and district levels. Assam is a priority state for the project.



## The Assam Context

- The public health sector in Assam is the main source of healthcare for almost four-fifths of all households in the state, with coverage higher in rural (83%) than in urban areas (61%).
- The Multi-Dimensional Poverty index in Assam is above the national average and the state has pockets of persistent impoverishment.
- Chronic and acute undernutrition is widespread among children under the age of five years; 36% of them are stunted and 17% are wasted.
- Twenty-six percent of women and 21% of men are underweight. Close to half the adult women are anemic.
- Undernutrition is particularly common in the younger age groups, in rural areas, and among the less educated.
- About one in five men smoke cigarettes (21%), and 17% smoke bidis.
- Nearly 85% of Assam's rural households rely on solid fuel for cooking.
- Nearly a fifth of Assam's people work in tea plantations with limited access to TB services.

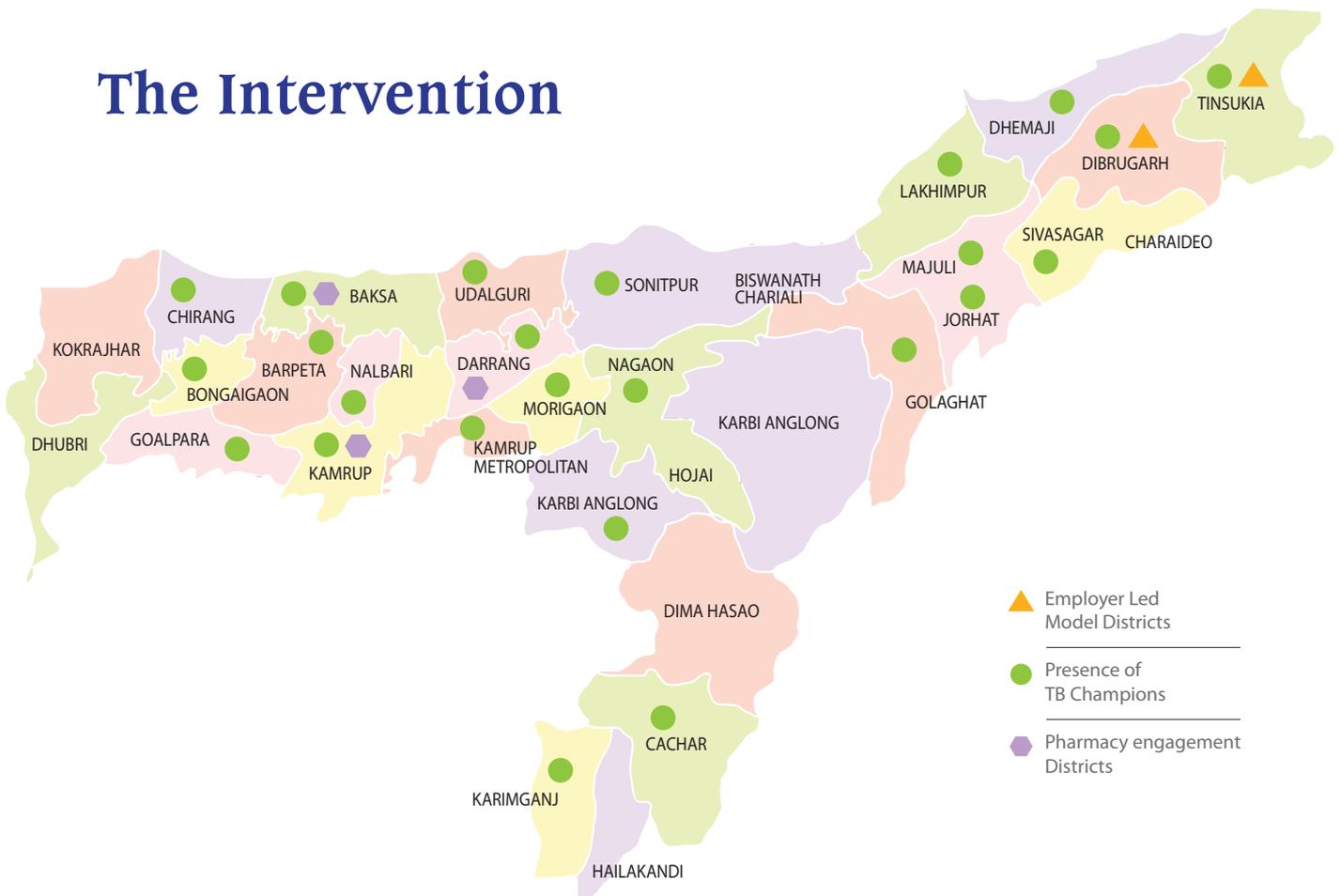
According to the Annual TB India Report 2018, 36720 people with TB were notified from the public sector and 3454 people from the private sector in 2017 – a total of 40174 people with TB in the state. Of this, 1664 notifications were of children. The NFHS-4 estimates from 2016 indicate that in Assam, 295 persons per 100,000 had medically treated TB, as reported by the respondents. The prevalence of medically treated TB was higher among men (406) than among women (182) and higher in rural (312) than in urban areas (183). The prevalence of medically treated TB was substantially higher among persons aged 60 years and above, and among persons in households using solid fuel for cooking (344).

Most people in Assam have heard of TB (89% of women and 92% of men), but among them, less than half (47%) of women and 60% of men knew that TB spreads through the air. About half (49%) of women and men (53%) had misconceptions about how TB is spread. Overall, 80% of women and 86% of men know that TB can be cured, and only 4% of women and 6% of men say that if a family member had TB, they would want to keep it a secret. According to various studies, 17-20% of tea garden workers in the state are estimated to be affected by TB.

In 2016, Assam was the first state to roll out the use of Bedaquiline for MDR-TB and was ranked the best performer in the Revised National Tuberculosis Control Programme from 2015-16 to 2016-17.

*(Data sources: NFHS-4, Niti Aayog and India TB Reports)*

## The Intervention





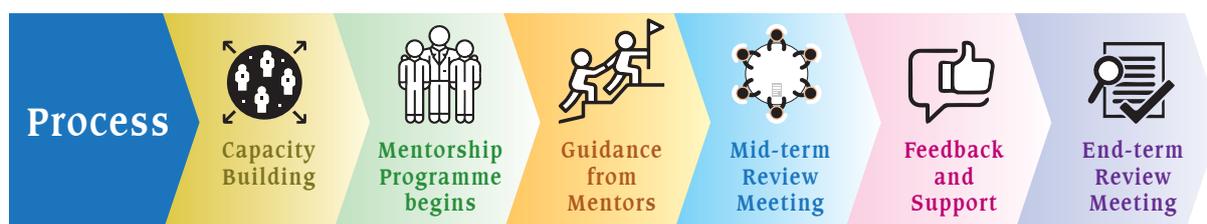
## To support and strengthen the community response to TB

### 1. From TB Survivors to TB Champions

In keeping with the project’s mandate to strengthen the voices of TB survivors, 54 TB survivors from 24 districts were trained through two capacity-building workshops held in July 2018 and February 2019, the first such in the state. Through the workshops, the TB survivors improved their understanding of TB and learned skills for grassroots level advocacy – to educate their communities, refer people with TB symptoms to diagnostic services, provide those with TB with psychosocial support, and work towards treatment literacy. Trained TB Champions have had multiple opportunities to make their voices heard – some have subsequently become members of various state and district TB Forums; others have spoken at conferences and meetings, including at the 50<sup>th</sup> Union World Conference on Lung Health held in Hyderabad in October 2019; and some Champions have participated in a Training of Trainers workshop organised by the Central TB Division.



### 2. TB Champions Mentorship Programme



Following the initial training, 30 TB Champions joined a systematic and structured six-month mentorship programme, rolled out in two rounds. The programme featured regular interaction between the trained TB Champion and a TB advocate or a ‘mentor’ — a person who understands the ecosystem in which the TB programme works at the state and district level. Eleven TB Champions from seven districts were enrolled in the first phase. Five mentors worked closely with their TB Champions to enhance their capacity to support people with TB, conduct community awareness and carry out advocacy with key stakeholders.

In the second phase of the mentorship programme, the TB Champions were motivated to reach and support a specified number of people with TB (at least 60 each) in their districts, conduct a definitive number of anti-stigma campaigns (minimum two) and advocate with frontline workers of the health system, district-level RNTCP staff, faith and opinion leaders, community and Panchayat leaders etc. The Champions also sensitised the assigned number of community members, including school and college students, other TB survivors and their families, women attending Anganwadi centres and members of Self-Help Groups, among others.

At the periodic review meetings held to take stock of the mentorship programme, State TB Cell officials and mentors together helped the Champions develop problem-solving skills to overcome field-level challenges. Subsequent to the roll-out of the mentorship programme, the State TB Officer sent a letter of support to the District TB Officers to facilitate the process of mentorship. The direction provided under the mentorship programme has enabled the TB Champions to effectively contribute to TB awareness efforts across the state.



## Anti-stigma campaign

In a bid to reduce the stigma and discrimination faced by people with TB, the TB Champions partnered with their respective District TB Cells, Panchayats, tea garden management, schools, mothers' groups, police forces and other establishments to carry out anti-stigma campaigns. Through the campaign, the TB Champions called on key stakeholders and community members to take a pledge to not stigmatise or discriminate against anyone with TB.

The District TB Cells for their part, sent out powerful messages by publicly felicitating the contributions of the TB Champions and speaking out about their courageous and valuable support in promoting the health and well-being of their communities.

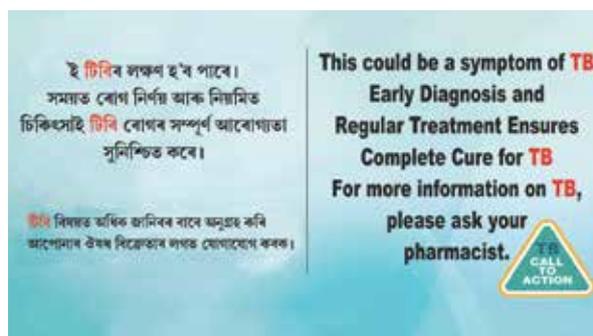


### 3. Forming and strengthening survivor-led networks

At the first capacity-building workshop held in July 2018, 25 TB survivors resolved to come together to form the first state-level network of survivors. At a meeting with the Mission Director, National Health Mission, Government of Assam, they declared the formation of the network and committed to working on behalf of people affected by TB. Subsequently named 'Jyoti End TB Assam' (JETA) network, it now has more than 200 survivors as members.

### 4. Engaging community pharmacists

In order to improve TB notifications, a consultative process was initiated in 2017 to bring together the State Drug Controller, the State TB Cell, pharmacy associations and the Assam Pharmacy Council to explore ways to engage pharmacists for case detection and public education about TB. Pharmacists from three districts were sensitised and encouraged to display information about TB, refer people with symptoms to the nearest facility and work in close coordination with the TB programme. The Association of Registered Pharmacists Assam, expressed their commitment for this effort and instructed all members to be actively involved in the TB response.



**To advocate for increased financial, intellectual and other resources for TB**

### 1. Employer Led Model (ELM) for TB Care and Prevention

The Employer Led Model (ELM) for TB, adapted from similar efforts by the National AIDS Control Organisation for HIV/AIDS, aims to establish a mechanism for involving employers of populations considered vulnerable to TB, such as tea gardens in Assam. The ELM was formally launched in Assam in August 2017 through a consultative meeting that brought together senior representatives from tea garden associations and state and district TB programme officials. Two districts – Dibrugarh and Tinsukia – were chosen for the pilot demonstration on account of the high concentration of tea gardens.

Between 2017 and 2019, through a collaborative effort involving the local administration in the districts, the State TB Cell, the Assam Branch of Indian Tea Association (ABITA) and Bharatiya Cha Parishad (BCP), more than 90 tea garden companies were sensitised on TB. Of these, 39 signed Letters of Intent (LOIs) with their respective district health officials. A majority – over 80% – have begun implementing ELM through active case finding efforts and awareness meetings among workers, their families and communities, and linking people with symptoms to the TB programme. Wherever possible, TB Champions from the tea garden areas have also participated in these efforts.

Through the ELM, employers have also committed to a workplace free of discrimination related to TB, and to sharing monthly reports with the District TB Cells. Regular sensitisation meetings, training workshops and review meetings for the tea gardens have helped strengthen their understanding of TB, and guided the translation of their commitment into action. A TB-free model garden programme was launched with six gardens from Dibrugarh district to create model ELM sites.



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“We are proud to partner with the Department of Health, the district administration and REACH to implement activities on TB through the ELM. We are committed to establishing a workplace free of any stigma and discrimination due to TB and to ensuring that our employees know when and where to seek care for TB.”

- *Dr. Purnananda Khound, Chief Medical Officer, Amalgamated Plantations Pvt. Ltd*

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## 2. Involving Elected Representatives in the TB Response

Advocacy efforts to involve elected representatives in Assam resulted in the participation of the highest elected official, the Chief Minister Shri Sarbananda Sonowal, at a roundtable meeting for Members of the Legislative Assembly (MLAs) held in October 2018. Speaking at the Assam State Assembly on the occasion, the Chief Minister urged his colleagues to actively contribute to ending TB in Assam by addressing TB in their respective constituencies, mobilising resources to meet gaps, encouraging the scale-up of positive innovations on TB and promoting public awareness about the disease. The meeting also saw the participation of the Speaker of the Assam Assembly, the Leader of the Opposition and more than 20 other MLAs.

Earlier in 2018, a similar roundtable meeting held in July in Dibrugarh brought together MLAs from the tea garden districts with TB Champions and health officials, for a discussion on the vulnerability of tea garden workers and migrant labour to TB. Following the meeting, Mr. Sanjay Kishan, MLA of Tinsukia, declared that he would spearhead efforts to make his constituency TB-free.



### 3. Inter-sectoral collaboration for TB

Through the project period, advocacy to promote collaboration among various governmental sectors was a priority, with the objective of mainstreaming TB awareness, prevention and care activities. The Director and other officials of the Tea Tribe Welfare Department were briefed on the need to provide social support to those from tea tribe communities affected by TB. In April-May 2019, over 160 Panchayati Raj representatives, including newly elected Gram Sabha leaders, were sensitised on the role they could play to support TB care and prevention efforts, and to support the reduction of stigma.

### 4. Engaging with journalists to improve the quality of reportage on TB

The news media is an integral actor in the overall public health ecosystem, and critical to promoting quality conversations on TB. In June 2017, REACH brought together 20 representatives from the national and local media in Guwahati with officials from the State TB Cell. The objective was to provide journalists with updated information on TB, including new developments in India's response to the disease, and to encourage ethical and appropriate coverage of TB stories in the state. The meeting also featured a



panel discussion with senior journalists and a TB Champion on the role that journalists could play in educating the public and to identify the ways in which media could give a voice to people with TB and reduce discrimination against them. One-to-one follow-up and continued engagement with journalists resulted in substantial reporting on TB-related issues in Assam. Efforts to engage with Doordarshan and All India Radio resulted in the development and broadcast of documentaries, talk shows and other programmes on TB.

## 5. Involving celebrities as TB Ambassadors

To reduce TB related stigma, raise the visibility of TB and educate the public on the basics of TB prevention and care, renowned musician Zubeen Garg was identified and engaged as a TB ambassador in Assam. In addition to a song on TB, Garg's powerful messages on TB currently feature in posters, TV spots and radio jingles. These communication materials have been widely disseminated by state and district officials as well as in tea gardens.



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“As the MLA of Tinsukia, I know that the tea garden community is especially vulnerable to TB. I am committed to working with REACH, the district TB programme and the community to improve awareness on TB and motivate people to access care and services for TB. We should also strive to end the stigma associated with the disease and I believe that elected representatives like myself can play a crucial role in achieving this.”

- *Mr. Sanjay Kishan, MLA, Tinsukia*

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“Over the last three years, the TB Call to Action Project has been successful in raising the visibility of TB in Assam and bringing together stakeholders who were previously not involved in TB. Our partnership with REACH has seen the rise of Assam's first group of trained TB survivors who are committed advocates on behalf of communities and the rollout of the Employer Led Model for TB, for the first time in India, in the two tea garden districts of Dibrugarh and Tinsukia.”

- *Mr. Anurag Goel, IAS, Commissioner and Secretary, Department of Health and Family Welfare, Government of Assam*

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## Key Highlights



*Project Launch by Assam Governor, August 2017*



*Mission Director, NHM Assam addresses TB Champions in Guwahati in July 2018*



*Assam's TB Champions at the valedictory meeting of the Mentorship Programme*



*The Chief Minister of Assam, Shri Sarbananda Sonowal speaks at a first-of-its-kind roundtable on TB in the state organised by REACH*

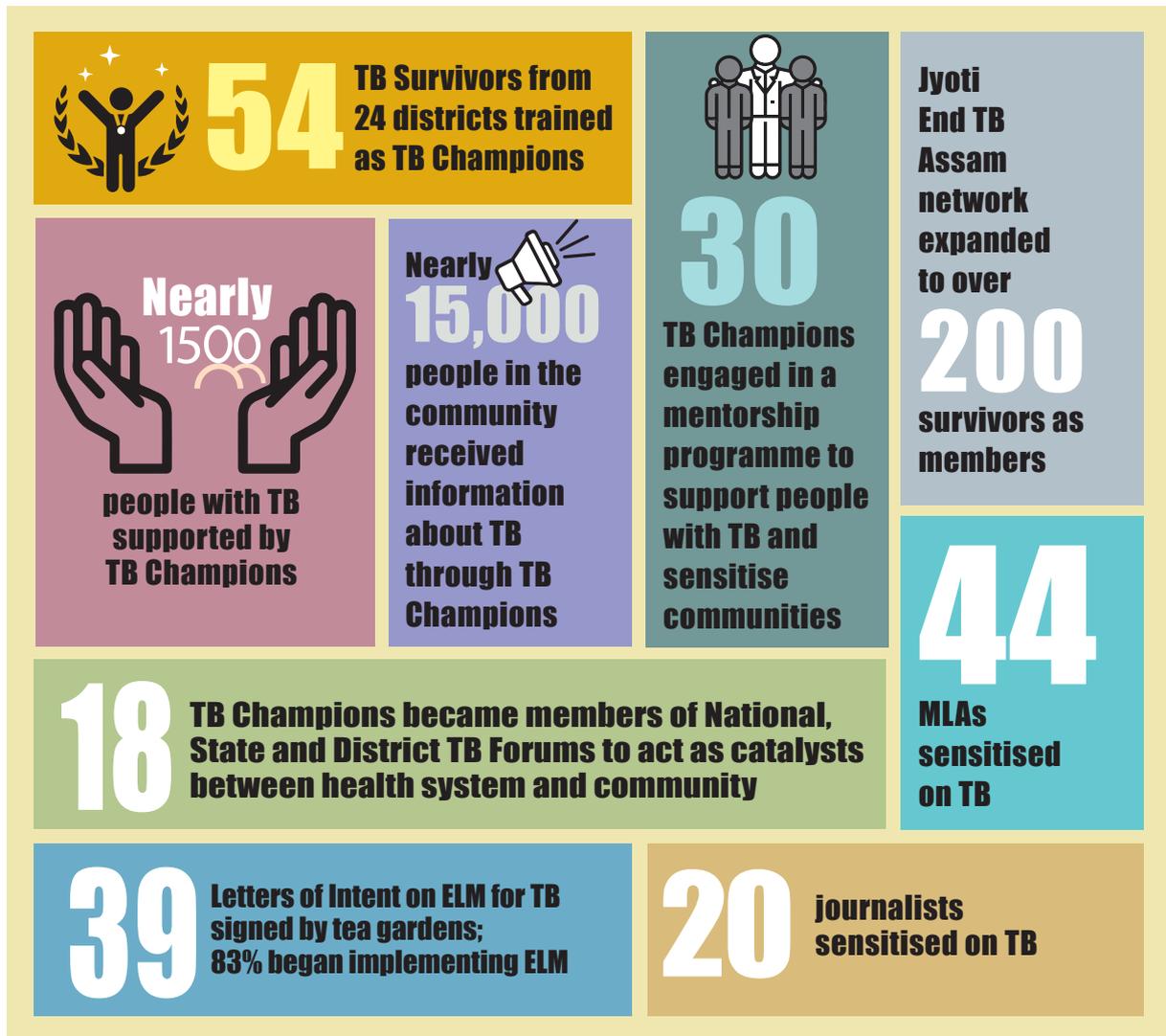


*TB Champion Minoti Puran speaks during a talk show on TB aired on Doordarshan*



*ELM activity at a tea garden underway*

## Key Results



“The Assam State TB Cell has worked closely with REACH towards our mutual goal of a TB-free Assam. Through its efforts over the last three years, REACH has supported the TB programme to strengthen the community response, engage the media and involve celebrities. Trained TB Champions are working closely with the RNTCP at the district and facility level to ensure that people with TB have access to timely services for TB.”

- *Dr. N.J.Das, State TB Officer, Assam*

“Through the Employer Led Model introduced by REACH, we have been able to involve tea gardens in Dibrugarh and Tinsukia and ensure their participation in the TB response. We are confident that through this partnership, we will be able to work with the tea gardens to address the needs of this vulnerable population and identify people with TB symptoms, reduce delays in diagnosis, and provide high-quality TB services.”

- *Dr. H. Sonowal, District TB Officer, Dibrugarh, Assam*

## Key Learnings

The TB Call to Action project has demonstrated the importance of bringing together a range of stakeholders for collective action. Through the different activities, processes of engaging previously unengaged stakeholders have been tested, demonstrated and documented, and have the potential for scale-up and expansion across India. The following are some key learnings from the project:

- ❑ Trained TB Champions are highly motivated to work with and among their communities and must be supported with monetary incentives and continued trainings.
- ❑ The fear of stigma or discrimination does not deter a TB survivor from working as a Champion. TB Champions are increasingly recognised as leaders within their communities and gradually become the go-to persons for all health issues, extending beyond TB.
- ❑ Being a TB Champion and working with the health system for the benefit of other people with TB is an empowering experience for a TB survivor. Most TB Champions reported advancement in their knowledge, skills and overall social standing.
- ❑ The RNTCP values the contribution of the TB Champions to all its activities and is willing to support the TB Champions to work jointly towards the goal of TB elimination at all levels.
- ❑ Survivor-led networks can harness the power of communities and provide a framework to synergise individual efforts, optimise cross-learning, and channel the collective voice of the members. Being a network member reduces the loneliness of having TB or life after TB.
- ❑ Companies in the public and private sector see the value of investing in the health of their employees and are keen to implement the Employer Led Model. Integrating TB into existing health activities, such as camps or regular screenings, is a simple starting point. Adoption of ELM on a larger scale needs a sustained inter-sectoral effort involving the department of health, mines and industries, the RNTCP and the administrative structure at the district level.
- ❑ Tea gardens are complex ecosystems with multiple stakeholders, each of whom has a distinct role to play. Tea gardens required considerable technical support from the district TB programme to regularly implement ELM activities.
- ❑ For an elected representative, TB must be contextualised in a broader community health setting, and seen as relevant to his or her constituents. Once aware of the scale and extent of TB's impact, most elected representatives are keen to be involved and assume the role of catalysts with the TB programme and the community.
- ❑ A biomedical response to TB is inadequate. Multiple stakeholders – survivors, elected representatives, industry leaders, the media, celebrities etc. – have distinct roles to play in eliminating TB and different strategies must be adopted to sensitise and involve them effectively. Engaging these players can amplify the TB response and accelerate TB elimination efforts across the country.

# Media Reporting



## TB awareness to help get rid of social stigmas

Kangkan Kalita | TSN

Guwahati: Minotti Puran is the mother of two children. Tuberculosis hit her after her marriage and during this time, not even her family stood by her. She went on to speak about how a TB survivor has to face the stigmas of our society and are forced to take treatments secretly.

To get rid of such ideas, a group of TB survivors are campaigning throughout the state to raise awareness about the disease. Over 60 TB survivors from over 20 districts led fortnight-long anti-stigma campaigns to raise public awareness. Since 2017, through the TB Call to

A tuberculosis awareness programme in Greenwood Tea Estate in Dibrugarh district

Action Project, the Resource Group for Education and Advocacy for Community Health (REACH) has trained over 70 TB survivors through capacity-building workshops and mentorship programmes in partnership with the State TB Cell and with the support of the United States Agency for International Development (USAID).

"They are organizing rallies and sensitization campaigns with anti-stigma messages. The awareness drives involved the participation of MLAs, panchayat presidents, school teachers, employers, self-help groups, tea garden management, mother groups, adolescent groups, patients and the community at large. The survivors urged the people to take a pledge not to stigmatize or discriminate against anyone with the disease," Arup Jyoti Kalita, state coordinator of REACH Assam, said.

Another TB survivor, Uday Ganger, said during an awareness program of Khobang tea estate in Tinsukia district, "We see TB with a different view because we have been victims of discrimination ourselves. It is high time we stand together against the stigma related to TB in our society." Survivors must motivate others affected by TB and convey the message that treatment is available and it is a curable disease, he added.

## Assam's TB Champions



“From a TB patient to a TB survivor, then a TB Champion and now a trainer for other TB survivors, I feel extremely privileged to consider myself an empowered advocate. The responsibility to carry forward the work towards elimination of TB in Assam is a very big one and I hope more TB Champions come forward and join me in this mission.”

- *Minoti Puran, TB Champion, Jorhat, Assam*

“Through this mentorship programme, I was able to reach out to the tea garden communities, who were previously unaware of TB. To support my community members who are affected by TB and give back to my community is extremely gratifying.”

- *Golga Sawra, TB Champion, Udalguri, Assam*



## About REACH

Resource Group for Education and Advocacy for Community Health (REACH) is a Chennai-based non-profit organisation established in 1999 in response to the roll out of the Revised National TB Control Programme (RNTCP) in Tamil Nadu. Through an unrelenting focus on TB for two decades, REACH has engaged various stakeholders for a multi-sectoral and comprehensive response to TB, including the Central TB Division, State and District TB Cells, private health care providers, business leaders, celebrities, the media, people with TB and affected communities. REACH has consistently supported the RNTCP in its efforts to prevent, detect and treat TB, by providing holistic care and support along the care cascade to people affected by TB.

With support from USAID, REACH has implemented the Tuberculosis Call to Action Project since 2016 in six priority states – Assam, Bihar, Chhattisgarh, Jharkhand, Odisha, Uttar Pradesh. Through this project, REACH has created a cadre of TB survivors and Champions who are actively engaged in the TB response, advocated for the participation of industries through the Employer Led Model, engaged elected representatives for greater attention to TB, facilitated inter-sectoral coordination between various departments (beyond health) and piloted TB Mitra, a unique mobile-based application for use by communities.

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