





# THE ACCOUNTABILITY LEADERSHIP BY LOCAL COMMUNITIES FOR INCLUSIVE, ENABLING SERVICES (ALLIES) PROJECT

# **NATIONAL IMPACT REPORT**











Prof. (Dr.) Urvashi B Singh
Deputy Director General
Central TB Division





भारत सरकार
GOVERNMENT OF INDIA
स्वास्थ्य और परिवार कल्याण मंत्रालय
MINISTRY OF HEALTH & FAMILY WELFARE
ROOM NO. G2 (GROUND FLOOR),
JEEVAN VIHAR BUILDING, 3, SANSAD MARG,
CONNAUGHT PLACE
NEW DELHI - 110001
ddgtb@rntcp.org
011-21400941

#### MESSAGE

REACH has been instrumental in supporting the National TB Elimination Programme (NTEP) to adopt and institutionalise the engagement of TB survivors as TB Champions. Trained TB Champions have been pivotal in providing essential peer support, reaching the most vulnerable communities, educating them about TB, combating stigma and discrimination, and facilitating access to essential services like nutrition support and linking them with social support interventions. These efforts have contributed to increased TB notification rates, improved treatment outcomes and reduced stigma.

The ALLIES project supported by USAID (2019-24) further strengthened Community Engagement by introducing community-led monitoring (CLM) for TB. Through a structured mechanism titled as "Community Accountability Framework (CAF)", it empowered communities to identify, address, and resolve gaps in TB care and services. CAF ensured that the voices and concerns of affected communities were heard and promptly addressed at district and sub-district levels, resulting in tangible improvements in TB care delivery, as outlined in this report. The responses from the health care workers and NTEP programme managers at different levels to the CAF, especially on receiving regular feedback from persons on TB treatment and working together with TB affected community to find and implement solutions for identified issues is also encouraging. Learning from the project and it's scale-up will enhance the health system's accountability and foster a culture of transparency and trust between communities and healthcare providers.

The project's commitment to inclusivity and equity is commendable. By addressing the specific needs of vulnerable groups, such as people with disabilities, the elderly and LGBTQIA++ communities, ALLIES has ensured that no one is left behind in the fight against TB. The project's engagement with other key stakeholders, including the media, elected representatives and industries, is also noteworthy. The media fellowship offered by REACH and The Employer Led Model implemented as part of ALLIES command special mention here.

The success of the CAF and the ALLIES project underscores the importance of integrating community accountability mechanisms into the broader national strategy for TB elimination. As we strive to achieve our TB elimination goals, it is imperative that we find ways to integrate and take to scale initiatives like CAF that empower communities, strengthen health systems, and ensure that every person with TB receives the quality care they deserve.

I congratulate the REACH team, all the TB Champions, Health care providers and State and District TB Officers and their teams for their powerful demonstration of a sustainable partnership between the health system and communities, to drive a positive change.

Prof. (Dr.) Urvashi B Singh)







## Dr. Nishant Kumar **Joint Director** Central TB Division





# स्वास्थ्य और परिवार कल्याण विभाग रवास्थ्य और परिवार कल्याण मंत्रालय Government of India **Department of Health and Family Welfare** Ministry of Health and Family Welfare

भारत सरकार

# Message

As we continue to make strides towards ending TB in India, I am heartened by our progress in incorporating community engagement as a powerful strategy in the National TB Elimination Programme. The voices of those affected by the disease are critical to amplifying public understanding of TB and are helping us improve health seeking behaviour in the society. TB Champions have shown us, over the last eight years, what they can achieve if we invest in building their capacity and engage them meaningfully.

The ALLIES project, implemented by REACH with support from USAID, has demonstrated the effectiveness of empowering communities to play a central role in improving the quality of care and services for people affected by TB. Over the past five years of implementation, the project has helped laying a strong foundation for community-led monitoring, as envisioned in the National Strategic Plan (NSP) for TB Elimination (2017-2025). Despite the COVID-19 setback, we have made significant progress in outcomes and have strengthened the TB Forums with voices from the TBaffected community, ensuring a more inclusive ecosystem.

I congratulate REACH for developing and operationalizing the Community Accountability Framework (CAF) model and placing TB-affected communities at the heart of it. This ensures that TB interventions are more person-centred, addressing real-world challenges such as stigma, treatment adherence, and access to care. By participating in decision-making, monitoring and advocacy, the TB Champions have helped tailor services to meet the needs of people with TB, enhanced accountability within health systems, and helped develop solutions that address gaps at district and sub-district levels.

We are committed to incorporating the community-led monitoring (CLM) mechanism into our TB elimination efforts by enabling TB affected community to provide critical feedback through different platforms such as TB Forums, and through TB survivor led networks. This requires a simple and adaptable approach that allows local customization, ensuring that TB elimination programme is responsive to the needs of different districts, each with its unique priorities.

I congratulate the entire REACH team and all the TB Champions for the successful implementation of the ALLIES project. I also thank USAID for continuing to invest in communities. I express my deep gratitude to all the States where the ALLIES project was implemented for their support, cooperation and valuable inputs. As we advance, the lessons we have learned and the structures we have built will guide us toward a TB Mukt Bharat, where community voices continue to shape and strengthen our national response.

(Dr. Nishant Kumar)

टीबी हारेगा, देश जीतेगा / TB Harega, Desh Jeetega

#### Message from Director, Health Office, USAID/India

Since 1998, the partnership between the United States and India has been pivotal in the fight against tuberculosis (TB). This collaboration, driven by a shared commitment to improving patient-centered diagnosis, treatment, and prevention, has focused on extending access and providing critical support to the most vulnerable populations.

The United States Agency for International Development (USAID) is proud to partner with the Government of India to achieve national and global goals. Together, we are enhancing case detection, improving treatment success rates, and addressing multi-drug resistant TB. Our efforts are bolstered by innovative solutions, including artificial intelligence and digital health technologies, ensuring a broad and effective impact.

A cornerstone of our efforts is the TB Champion program, which has evolved from a pilot initiative by REACH in 2016 to a nationwide movement embedded within India's National TB Elimination Programme. USAID is proud to support the ALLIES project, which exemplifies a shift toward socially inclusive and gender-responsive approaches, with TB Champions providing essential peer support and psychosocial assistance to TB patients and their families. Their roles became especially critical during the COVID-19 pandemic, as they emerged as trusted sources of health information in their communities.

Understanding the importance of addressing gender disparities, USAID has developed a gender-responsive TB program that integrates gender-sensitive messaging and strengthens the capacities of healthcare workers to overcome gender barriers to TB detection, diagnosis, and treatment. TB Champions are now at the forefront of challenging stigma and using creative platforms to foster an inclusive environment. USAID remains committed to promoting equity and social inclusion, with a focus on vulnerable groups, including persons with disabilities and the elderly.

On behalf of USAID, I express my sincere gratitude to the leadership of the National TB Elimination Programme for their dedication to community engagement and to the REACH team for their visionary efforts. Above all, I commend the TB Champions for their unwavering dedication and inspiring contributions, which are at the heart of this movement. USAID is proud to support this initiative, which has contributed to a more inclusive, accountable, and resilient TB response in India.

Michelle Lang-Alli

Michelle Lang-Alli Health Office Director USAID/India Message from Director, REACH

Innovate, Ideate, Implement – this philosophy drives the core of REACH's work. Over our 25-year journey—from our initial

private sector engagement model in Chennai to the USAID-supported TB Call to Action project—one key lesson emerged: the need for involving the community more proactively. This involved not just engaging the community, but empowering

them to lead initiatives and strategies for the delivery of services intended for them.

This led to a new beginning, and we developed the first structured mechanism for engaging affected communities - the TB

Champion model - placing them at the centre. This initiative gave rise to the ALLIES project—Accountability Leadership by Local communities for Inclusive, Enabling Services—supported by USAID. ALLIES is a distinctive effort focused on

strengthening health systems in tandem with community systems strengthening through the Community Accountability

Framework.

I am pleased to present the National Impact Report of ALLIES (2019-2024), which details how this community-driven,

multi-sectoral initiative has made significant contributions to India's TB response.

REACH recognises and values individual needs over a one-size-fits-all approach, which is why the Community

Accountability Framework (CAF) has been so impactful. By reaching out to each person with TB and understanding their

challenges and experiences with the Quality of Care and Quality of Services along the TB Care Cascade, the project—implemented by trained TB Champions—provided valuable insights into the needs of the TB-affected community

and highlighted gaps requiring local, tailored, and sustainable solutions.

Although implementing CAF presented challenges, our efforts to engage broader stakeholders and secure their

commitment to the TB response have been crucial. This has amplified community participation and brought much-needed

attention to changes both on the ground and at the policy level. As a result, the overall experience of people with TB has improved. Additionally, the work done to enhance gender responsiveness, address stigma, and tackle challenges faced by

vulnerable groups—such as people with disabilities, the elderly, and those living alone—has advanced holistic TB care.

Survivor-led networks, now at various levels of growth and empowerment, have become integral to the NTEP and

represent an enduring structure for driving community-led interventions.

I extend my heartfelt thanks to everyone who has supported the ALLIES project, particularly our TB Champions, who have

been pivotal in driving these efforts. We are grateful to the National TB Elimination Programme, particularly the leadership at

Central TB Division and in all our project states and districts, for acknowledging the significance of community engagement. Their vision guided the ALLIES project, and their constant support was instrumental in its successful implementation. We

are deeply thankful to USAID for their sustained investment in communities, and for the trust they have reposed in REACH

over the last several years. I would particularly like to recall the immense contribution of Amrita Goswami of USAID to the

ALLIES project, and to our work with communities in general - we could not have achieved what we did without Amrita, and

we will always remember her with deep gratitude.

We remain committed to working together, with all partners, for a community-led, person-centred TB response.

Dr. Ramya Ananthakrishnan, MD

Zamya Manthakushman

Director - REACH

#### Message from Project Lead, ALLIES

True to its name, ALLIES (Accountability Leadership by Local communities for Inclusive, Enabling Services) focused on TB elimination by placing the TB-affected community at the centre and mobilising all stakeholders, or "allies," for a multi-sectoral, collaborative TB response. Supported by USAID, the project's vision was to advance the National Strategic Plan's goal of strengthening community engagement in TB elimination efforts.

ALLIES succeeded in fostering a culture of ownership and accountability through the innovative Community Accountability Framework (CAF), a community-led monitoring system with a solutions-based approach. Trained TB Champions used the CAF tool to gather feedback from over 50,000 individuals with TB throughout the project, providing valuable insights to district and state NTEP teams. Additionally, TB Champions sought local, sustainable solutions to address identified gaps. Examples include installing smokeless chulhas to improve lung health in Chhattisgarh and mobilising over 20 lakh rupees worth additional nutrition support for people with TB in Tamil Nadu. Consequently, TB Champions emerged as true leaders and agents of change, operating with strength as TB survivor-led networks to highlight critical community issues and advocate for change. Their mission extended beyond TB prevention to promoting a long, healthy, and economically sustainable life for people with TB. Network members assisted individuals with TB and disabilities in obtaining disability certificates, pension, and livelihood support, raised awareness among transpersons and engaged them in TB-related activities, and even led a youth campaign to end TB.

The project made notable progress in fostering inclusivity and equality, ensuring that no one was left behind. Rapid assessments on TB and disability, TB in the elderly, support to the NTEP to develop and operationalise the National Framework for a Gender-Responsive Approach to TB, and Strategy to End Stigma and Discrimination associated with Tuberculosis were key steps in this direction. Sensitised industries, elected representatives, District TB Forum members, and media representatives all renewed their commitment to the goal of a TB Mukt Bharat. We hope that the integrated approach initiated by ALLIES, driven by large-scale awareness and community advocacy, will continue to promote community accountability and local ownership, ensuring long-term sustainability.

With this, I am delighted to present the National Impact Report for the ALLIES Project (2019-2024). Please read the report to see the unwavering dedication of our team members and TB Champions in enhancing community engagement. I am deeply grateful to the Central TB Division, USAID India Health Office, special gratitude to Late Ms. Amrita Goswami for her untiring support and guidance, WHO India office for technical support, Partners and all the TB Champions for their steadfast commitment and tireless efforts in supporting people with TB.

Mr. Subrat Mohanty
Project Lead, ALLIES
REACH

Suborst Mohanly



# **Contents**

SECTION 1

About the ALLIES **Project** 



Creating a Culture of Ownership and Accountability



## SECTION 3

Fostering a Community-led, Holistic Approach to TB Care

PAGE 20





## SECTION 4

Strengthening TB Survivor-led Networks

PAGE 28

# SECTION 5

Leaving No One Behind

PAGE 32

# SECTION 6

Mobilising Multisectoral Action

PAGE 39

# SECTION 7

Events and Key Highlights

PAGE 44

## SECTION 8

ALLIES Publications and Films

PAGE 49





# **About the ALLIES Project**

## **Background**

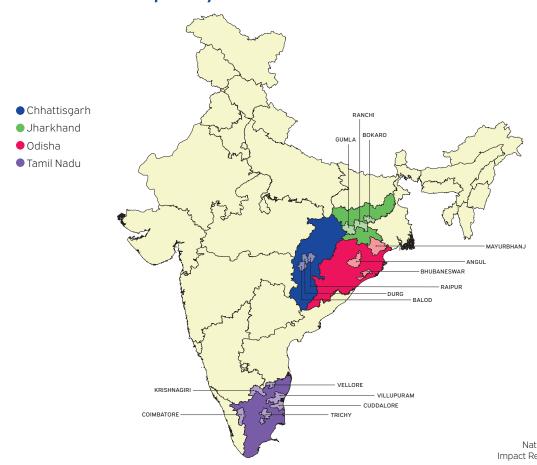
The Government of India (GOI) rolled out the National Strategic Plan (NSP) for TB Elimination (2017-25) to accelerate the efforts towards the elimination of Tuberculosis (TB) from the country. The comprehensive Detect-Treat-Prevent-Build approach proposed by the NSP brings focus on activities that are designed to plug gaps in the TB care cascade by engaging the private sector, communities and other stakeholders.

For the past two and a half decades, the Resource Group for Education and Advocacy for Community Health (REACH) has been a key partner in the country's fight against TB. Working in close collaboration with the National TB Elimination Programme (NTEP) at the national, state and district levels, REACH has placed the persons affected by TB as the central focus for all actions and decisions, giving primacy to being guided by their needs.

REACH strengthened the community response to TB by designing and piloting the TB survivor-Champion model as part of the TB Call to Action Project supported by USAID (2016-2020). As part of the project, REACH also advocated for increased resources for TB by involving industries, Elected Representatives (ERs), the media and others.

Having built a rich repertoire of experiences, REACH implemented The Accountability Leadership by Local communities for Inclusive, Enabling Services (ALLIES) project between 2019 and 2024. The project was implemented in collaboration with NTEP and with support from the United States Agency for International Development (USAID) in 15 districts of four priority states - Chhattisgarh, Jharkhand, Odisha and Tamil Nadu.

Figure 1: 15 districts of four priority states



## **Aim of ALLIES**

The ALLIES project strove to create an **enabling environment for TB elimination** by leveraging **community action** as an ally to build a **culture of accountability** and **empower communities**, including those most marginalised.

Central to the ALLIES project was the Community Accountability Framework (CAF), intended to improve the Quality of Care (QoC) and Quality of Services (QoS) for people and communities affected by TB, by adopting a solution-oriented, community-led monitoring approach. The CAF was envisaged as a bottom-up approach to the World Health Organization's (WHO's) Multi Sectoral Accountability Framework and is based on the key principles of integrity, inclusivity, effectiveness and actionability.

## **Project Objectives**

To create powerful advocates as key change agents or community enablers who can undertake strategic advocacy for enabling environments at multiple levels to shape rights-respectful, gender and ageresponsive TB services

To establish communityowned mechanisms to monitor quality of TB care and services, and give feedback to the programme for timely responses, helping institute accountability and strengthening community empowerment

local solutions and resources in response to identified needs, such as counselling for behaviour change, nutrition, local support groups, social services, etc.

To generate

To promote discourse on enabling the policy, regulatory and financial environments to support TB elimination and reduce TB-related stigma/discrimination at state and national levels.

Figure 2: ALLIES: Community Accountability Framework



#### ALLIES at a Glance\_\_\_\_



Community Accountability
Framework to improve the quality of
TB care and services



Identifying, training and engaging **TB survivors as TB Champions** 

Strengthening capacity of TB Champions to support their communities through **unique trainings** on counselling, rights-based approaches to TB, communications skilling, counselling, using Data for Action, organisational development, advocacy, TB and disability, gender dimensions of TB, livelihood skilling, etc.







Building health system capacity to provide person-centred care through the Achieving Excellence in TB Care and Services (AETBCS) curriculum



Engaging Elected Representatives, industries and media for multi-sectoral action



Providing technical support to NTEP to strengthen and operationalise the National Framework for a Gender-responsive Approach to TB



Generating evidence on various social dimensions of TB through **special interventions** on TB and disability, TB in the Elderly and Differentiated Care Model (DCM), among others



#### **KEY RESULTS**



Quality of TB care and services improved in

153

TB Units (out of 198 TB Units in 15 districts) which were covered through CAF



50,000+
people with TB on quality

of TB care and services



Support and information on TB provided to

470,406

people in the community through TB Champions



TB survivors trained as TB Champions



991

healthcare workers and NTEP officials trained on AETBCS



180+

stories written by

58

journalists who received the Media Fellowship



2,287

Elected Representatives sensitised on TB, including **26** Members of Legislative Assembly (MLAs), **6** Members of Parliament (MPs), **2** Mayors, **2,051** Panchayati Raj Institution (PRI) members and 166 Corporators/Councillors



94

Companies joined the Employer-Led Model (ELM)



416

journalists sensitised through media roundtables



Rapid assessments undertaken on TB in the Elderly, and TB and Disability



2,000+

people with TB assessed for vulnerabilities in Mayurbhanj, Odisha and Chennai, Tamil Nadu as part of the Differentiated Care Model

# Creating a Culture of Ownership and Accountability



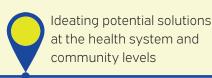
ALLIES made successful strides towards building accountability, and enhancing coverage and effectiveness of the TB programme, alongside generating demand for strengthening community's confidence in TB services in the project's intervention districts.

## **Community Accountability Framework**

The CAF, first designed and piloted through the ALLIES project, is a community-led monitoring model which helps improve Quality of Care and Quality of Services for people and communities

affected by TB. The CAF model adopts a multi-step 'Identify-Ideate-Implement' approach with three distinct stages, bringing together the health system and the community to:







Implementing collaborative solutions involving either individual actions and/or health systems strengthening

#### **Designing CAF: The process**

REACH's experience with TB Champions through the TB Call to Action project supported by USAID established the importance of building agency at the grassroots level. The initial development of the CAF model involved two key actions: identifying the key actors involved for a health system-community partnership; and articulating their roles with clarity in the feedback process. These key actors included:

- People with TB and their families
- TB survivors-Champions and survivor-led networks
- Community-at-large
- Healthcare providers (ASHAs, STS, Lab Technicians, Medical Officers, CHOs and MPWs)
- Health system administrators and leadership (State and District TB Officers and other senior officials)
- Key influencers and persons with authority (PRI members, urban administrators, etc.)



Developing CAF as a model for implementation was a consultative and participatory process, involving interviews with key stakeholders, along with community consultations on quality of care and services. The consolidated findings

on these consultations resulted in a draft CAF curriculum which defined communityled accountability, identified training requirements, and the potential process for operationalising CAF.

#### Rapid Results Initiative: A pilot demonstration of CAF

A Rapid Results Initiative (RRI) was designed to validate the assumptions of the processes to operationalise and scale up CAF through the 3-I approach – Ideate, Innovate and Implement. The RRI process was rolled out in 2020 during the COVID-19 pandemic. A draft tool was developed

and one TB facility was selected in each of the four priority states. TB Champions interviewed over 60 people with TB at select facilities. Findings from these interviews were analysed and used to strengthen the tool and inform the design for scale up of CAF across districts.

#### **Building community capacity on accountability**

TB Champions
were identified
and trained on the
CAF curriculum.
The training was
practice-oriented
and introduced
various concepts

to the participants

What is accountability?

Meaning of accountability in TB Care

How an accountable system is an ideal interplay between those in power fulfilling their responsibilities and those who are served being aware of their rights

A Quality Assessment Tool as a first step in the CAF process

In-person role plays

Block Action Plans – how to monitor and deliver on a set of activities.





TB Champions were then engaged in their respective blocks to meet people with TB and assess gaps in quality of care and services using the Quality Assessment Tool.

One of the major learnings from the initial CAF process was that there are latent resources within the community which TB Champions can tap

into, once they identify the problem. The TB Champions worked with NTEP to identify these local solutions to support the community. Some examples of such local solutions are meeting nutritional needs, organising alternatives to local transport systems, linking people to appropriate support systems, among others.

#### **CAF Quality Assessment Tool**

The CAF Quality Assessment Tool is structured around five key parameters that impact the quality of care and services: Timeliness, Access, Quality of information received, Attitude of care providers, and Attitude of families and communities.



Through CAF, we are identifying the challenges faced by people with TB and are working closely with the health system to find local solutions. We are able to support people even in remote and neglected areas.

**Purushottam Sahu**TB Champion, Raipur district

Within each parameter, there are multiple questions that seek to understand the experience of a person with TB along the care continuum and most questions have follow-up probes to gather the necessary information. In addition, a background section captures basic demographic details about people with TB and their current TB status

TB Champions were trained to administer the tool empathetically and to record responses accurately. The process of administering the tool also provided them the opportunity to improve treatment literacy and help people with TB understand what to expect through the treatment period.

# Impact of CAF\_

CAF reached over **50,000** people with TB and created an ecosystem where feedback on the quality of TB care and services was sought directly from those using services. It was presented to NTEP where all key stakeholders come together to find active solutions. The identified gaps were mapped through **4,123** Block Action Plans (BAPs) and steps were taken at the individual, family, community and system levels to address the gaps. All the gathered data was shared with the district NTEP teams and solutions were identified jointly.

A significant increase was observed across the five key parameters from the baseline figures (in October - December 2021) till the end of the project, indicating an improvement in the overall quality of care and services.



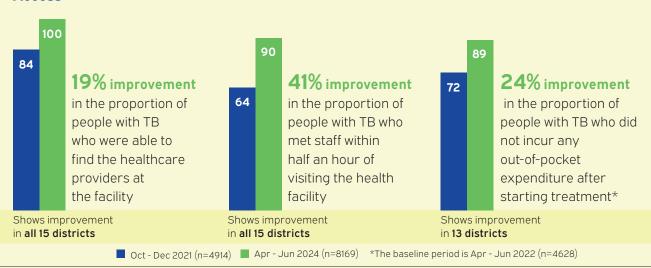
We have seen the role of TB Champions evolve over the last five years. TB Champions are a tremendous bridge between the programme and the community, and therefore the ideal people to facilitate feedback on our services. Today, through the CAF model and the efforts of the TB Champions, we are getting real-time feedback that helps us understand how we can constantly keep improving our services.

**Dr. S.M Zafarullah**District TB Officer, Bokaro, Jharkhand

#### **Timeliness**



#### Access



#### **Quality of information**

90 17% improvement in the proportion of people with TB who were told about follow up visits after completion of treatment

Shows improvement in 11 districts

95 23% improvement in the proportion of people with TB who received information on Isoniazid (INH) Prophylaxis

Shows improvement in all 15 districts

42% improvement in the proportion of family members of people with TB 43 who were counselled on TB Preventive Treatment (TPT)\*

Shows improvement in 12 districts

99

Oct - Dec 2021 (n=4914) Apr - Jun 2024 (n=8169) \*The baseline period is Apr - Jun 2022 (n=4628)

81 10% improvement in the proportion of people with TB whose sputum was tested after completion of intensive phase of treatment

Shows improvement in 12 districts

#### Attitude of healthcare providers

84 18% improvement in the proportion of people with TB who reported that they were satisfied with the behaviour of health staff

Shows improvement in all 15 districts

16

225% improvement

in the proportion of people with TB who were aware of Ni-kshay Sampark Helpline Number

11% improvement

in the proportion of

that their employers

were supportive

people with TB reporting

Shows improvement in 12 districts

Oct - Dec 2021 (n=4914) Apr - Jun 2024 (n=8169)

#### Attitude of communities

72

38% improvement

in the proportion of people with TB who reported that their friends and community behaved kindly towards them

Shows improvement in all 15 districts

Shows improvement in 13 districts

87

Oct - Dec 2021 (n=4914) Apr - Jun 2024 (n=8169)

## Assessing the Potential of CAF for Scale-up

Based on the feedback on CAF in the project districts, in 2023, the ALLIES project piloted variations of the CAF model to make simpler, accessible versions of the CAF tool. These variations included:

- A Comprehensive Assessment Tool (CAT)
   which included components of vulnerability
   assessment, TB and disability, and Quality of
   Life parameters. The tool was administered in
   all 153 TUs of 15 districts.
- A CAF for people with drug-resistant TB
   (DR-TB) adapted to get specific feedback from this group.
- CAF Lite Tool adapted from the CAF tool with reduced indicators to identify gaps in 5 parameters – timeliness, access, information, attitude of care providers and family, and community's attitude towards people with TB. The tool was administered in 35 non-ALLIES TUs of 15 districts.

## **Comprehensive Assessment Tool**

CAT was administered to

13,838

people with TB in a 13-month period. The key findings of the assessment included:

Among the people with TB interviewed:



34%



17% were over 60 years old

Other illnesses/ diseases reported:



8% had anaemia



**6.9%** had hypertension



Significantly higher prevalence (16.6%) among those over 60 years old



Slightly higher prevalence among males (15%) than females (11%)

#### Support needed by vulnerable populations:



2.7%

of people with TB reported having some kind of disability



**55**%

of persons with disabilities and 39%

of elderly individuals required travel support from their residence to a health facility **29**%

of women needed to be accompanied by a guardian during their health facility visits

Challenges/ Issues faced:



22%

of people with TB experienced difficulty walking 15%

faced challenges with daily activities such as dressing or washing themselves 30%

reported experiencing pain or discomfort 25% suffered from anxiety or

depression

# **CAF** for People with DRTB

Over an 8-month period (November 2023 to June 2024), the tool was administered to 156 people with DRTB across 4 districts (Raipur, Ranchi, Bhubaneswar and Coimbatore Districts). Based on the responses:

were aware of their drug-resistant status
77% reported that their Pre-Treatment Evaluation (PTE) was completed
42% were informed about Line Probe Assay (LPA) tests
29% received travel incentives for diagnosis and treatment
47% experienced side-effects during treatment
were given the option of receiving medicines at a treatment centre nearer to their homes
74% were initiated on treatment within 15 days of receiving their test results



# STORY 1 Bringing TB care to the Doorstep

For the tribal communities in Gumla district, Jharkhand, battling TB extends beyond just medical treatment — it involves overcoming significant geographical isolation and financial hardship. Language barriers, cultural hesitations, and inadequate access to proper nutrition contributed to higher out-of-pocket expenditures, driving many people with TB to seek costly private treatments or rely on local quacks.

Praveen Sahu, a TB Champion, recalled his initial experience with TB. "When I had TB and before becoming a TB Champion, I thought out-of-pocket

expenses were just part of the process. But after meeting people in Adivasi areas, I realised how big an issue it was. People were spending so much just to get to the TUs, let alone on treatment."

The challenges were particularly acute in Kamdara and Gumla TB Units, where many people with TB had to travel long distances. With only one bus service operating in the morning and returning in the evening, a single visit could mean losing an entire day's wages. "Many Persons with TB simply couldn't afford to come for regular medication or even to take TB preventive treatment," Praveen said.

# Challenges

- Geographic isolation: The remote, tribal, and hilly locations made it difficult for people with TB to reach healthcare facilities. The cost of transportation to TB units was a major financial burden.
- Language and cultural barriers: Many people
  with TB from particularly vulnerable tribal
  groups (PVTG) were hesitant to approach
  doctors due to language differences and social
  barriers. This led them to rely on informal
  treatments in their local communities, which
  increased their out-of-pocket expenditures.
- Nutritional deficiencies: There was a lack of awareness about the importance of proper nutrition during TB treatment. People with TB often resorted to buying expensive nutritional supplements from private pharmacies, adding to their costs. Further, many wrongly

- believed that they should not eat meat during treatment
- Side-effects of TB medication: Common sideeffects such as vomiting, itching, and jaundice led many people with TB to seek additional treatments outside the public health system, further increasing their expenses.

To address the multifaceted challenges in Gumla district, the TB Champions and Senior Treatment Supervisors at Kamdara and Gumla units implemented a range of strategies as part of CAF. These interventions focused on improving access to care, enhancing adherence, and reducing out-of-pocket expenditures:

Bringing care to the doorstep: Mobile health units were deployed to reach remote tribal areas eliminating the need for people with TR

## **CAF CASE STUDIES**

- to travel long distances. Healthcare providers, including doctors and nurses, travelled to these areas to provide TB treatment and follow-up care directly to people with TB.
- Speaking your language: TB Champions and Senior Treatment Supervisors identified the need for healthcare workers who could speak the local tribal languages and understood the cultural context. Trained nurses from tribal communities were employed to provide counselling and medical care, ensuring that people with TB were comfortable and well-informed. "We got healthcare workers from within the tribal communities people who could speak the local language and were trusted by the community. This made it easier for people with TB to open up and get proper counselling," Praveen explained.
- Making nutrition accessible: In Kamdara TU, people with TB were often prescribed vitamin supplements, which they had to buy from private pharmacies. This pushed their expenses higher. "Once we identified the gap, we made sure that supplements were provided directly by the hospitals, so people with TB didn't have to spend money outside," Praveen said. In Gumla TU, the focus shifted towards promoting protein-rich diets. Many people believed that people with TB shouldn't eat meat, which led to poor nutrition. The health teams conducted extensive counselling to dispel these myths. "We counselled them and stressed that they need protein-rich foods that are essential for recovery," said Senior Treatment Supervisor (STS) Sudhanshu Mishra. Through the Nikshay Mitra scheme, people with TB received monthly nutrition baskets containing dal, chana, groundnuts, jaggery, and cooking oil.
- Active Case Finding (ACF) camps: ACF camps were organised in tribal areas to increase awareness about government healthcare

- services and TB treatment availability. These camps played a crucial role in early diagnosis and reducing the reliance on private, often more expensive, treatment options.
- Side-effect management and medication counselling: TB medication often comes with side-effects such as vomiting, itching, and jaundice, which led people with TB to seek additional treatment from private providers. To prevent this, the health teams began addressing these issues upfront. "During initial counselling, we provided people with TB with paracetamol for fever and gas medicine as a precaution, so they wouldn't need to seek expensive private treatments," explained STS Sudhanshu Mishra.

Additionally, early co-morbidity testing was introduced. People with TB were screened for conditions like diabetes, hypertension, and anaemia right at the start of their TB treatment. "We made sure that people with TB received the necessary medications for these conditions from the beginning, so they wouldn't have to deal with these issues later on," said Gumla STS Sudhanshu Mishra. This approach not only improved health outcomes but also saved people with TB from incurring additional costs. Sahiyas (ASHA workers) were trained to counsel people with TB, ensuring that they did not seek out unverified treatments.

The strategies at Kamdara and Gumla units have significantly reduced out-of-pocket expenses for people with TB. In Gumla TU, the proportion of people with TB not incurring extra costs was 85% in 2024, compared to 27% in 2021. This improvement was due to promoting nutrition-rich diets over expensive supplements. Full enrollment in the Ni-kshay Mitra scheme also helped reduce costs, further improving accessibility and affordability for people with TB.

#### **Success Story**

One notable success was a young woman who had been working in Delhi and was diagnosed with TB upon returning to her home in Gumla district. Due to a nurses' strike at the time, she struggled to receive her medication. Another person with TB connected her with a TB Champion, who coordinated her care, ensuring that she received proper treatment despite the disruption in services. The person with TB also had liver issues, which were diagnosed and treated without her needing to spend on the treatment. Today, she has fully recovered and resumed her work outside the state.

# STORY 2 More Aware, More Empowered

When Arun Nayak first started working as a TB Champion in Odisha's Angul district, very few people he surveyed for the CAF were aware of the Ni-kshay Sampark Toll Free Number. "This is a crucial facility for people with TB, but unfortunately, it wasn't really being disseminated," Arun said. In fact, NTEP staff, who are usually overworked, were wary of more people knowing about the helpline, as they believed it would lead to complaints against them being escalated to the Central TB Division. "They saw it as a problem, rather than a right of people with TB," Arun recalled. With CAF, awareness about the number among people with TB in Angul district was reported at 78% in April - June 2024, compared to 24% in October - December 2021.

Arun had learnt the importance of the helpline during his training on CAF. Operated by the Central TB Division, this helpline is meant to answer any TB related queries, including information about side-effects, updates on follow-ups, and tracking the status of NPY payments. Arun and other TB Champions in Angul district raised the gap in awareness with the NTEP, and asked for the number to be printed on the TB ID cards so people had quick access to it and for improved awareness. The suggestion wasn't immediately accepted, but they started using several strategies to improve awareness in the meantime:

- TB Champions started writing down the helpline number on the patient ID cards as well as treatment cards.
- Awareness about Ni-kshay helpline number was raised through community platforms like gram sabha meetings.
- TB Champions created several wall paintings where the number was promoted, including on the walls of the District Health Centre

As the awareness increased, more people started using the helpline number. "It took a lot of discussions with the TB Units, a lot of convincing that this wasn't in fact a bad thing," Arun explained, "and finally, they agreed to print the numbers on the ID cards." The stock of ID cards with the helpline number printed on them arrived six months later.

Preethi Mahapatra, an STS from Angul district said, "Earlier, people with TB or their families would reach



out to me or my colleagues repeatedly to know the status of their Direct Benefit Transfer (DBT) under NPY. Now, many people just use the toll free number, and this reduces our workload and we can focus on providing healthcare."

The awareness has increased not only in Angul, but in Mayurbhanj and Bhubaneswar districts as well. In Mayurbhanj, TB Champion Binay has created over 100 wall paintings to improve awareness about the number. The awareness has had several impacts:

- People with TB often encounter side-effects
  from the drugs which can lead to anxiety, and
  in some cases, drug interruption. The helpline
  helps clear their doubts regarding this and gives
  them knowledge on how to deal with these sideeffects, resulting in better treatment outcomes.
  Arun cited the example of a person who faced
  side-effects late in the night, and his neighbour
  called the toll free number to find a way to help
  him.
- Another positive outcome has been improved cough hygiene practices among people with TB. Gaining knowledge about cough etiquette through the helpline has helped prevent the spread of the disease.
- In some areas, people depend on middlemen
  to update them on DBT for various schemes,
  including MGNREGA payments. The middleman
  usually gets bank passbooks updated, tracks
  payment schedules, and takes a cut on deposits
  that are made for various schemes. However,
  with the Ni-kshay Sampark Number, people with
  TB and their families are able to track their DBT
  under NPY over phone, and are able to avoid
  having to pay the middleman.

# STORY 3 A Weighty Intervention in Vellore

When TB Champion Suryapriya took the CAF tool to people with TB in Vellore in 2021, she noticed a recurring theme over a period of four months. Many of the people with TB she surveyed reported that their weight wasn't being monitored regularly. As a TB survivor, Surya knew how important it was to monitor weight during the course of the treatment. Treatment is based on weight-bands, i.e., the medication depends on the weight of the person, and getting the right dosage could mean the difference between a full recovery and continued suffering.

"I analysed the data and took this issue up with the STS and the District TB Officer (DTO) at one of our



monthly review meetings," Surya recalls. According to the insights she had gathered while working with the CAF tool, this gap was because of three reasons:

- 1. Absence of NTEP Staff at CHCs and PHCs:
  The NTEP staff were not always present in
  Community Health Centres (CHCs) and Primary
  Health Centres (PHCs). Consequently, the
  general health staff, who were not specialised
  in TB care, were unaware of the importance of
  regular weight checks for people with TB.
- 2. Medication Collection by Treatment
  Supporters: Many people with TB did not come themselves to collect their medication. Instead, treatment supporters, often family members, would collect the medication on their behalf. This was especially common among older people with TB, those who were breadwinners and could not afford to miss work, and those who lived in remote areas. This practice prevented regular weight checks for these people.
- 3. Lack of Awareness in Pharmacies: Pharmacies dispensing TB drugs in PHCs were not checking the weight of people with TB before giving out medication. This oversight led to people with TB receiving incorrect dosages based on outdated weight records.

The response of the state mechanism was proactive, says Senthil, the District Strategist for CAF in Vellore. The DTO and other officials took immediate steps to address these gaps. "They ensured that NTEP staff were consistently present in all healthcare centres, especially in Tirupathur CHC, to oversee the weight recording process," he explained.

"We also issued directives to all PHCs, including those in remote areas, mandating that pharmacies must check and record the weight of people with TB before dispensing medication," said Gobi, the STS of Tirupathur TB Unit who was one of the officials who took action after TB Champions presented this gap. "While initial compliance was slow, repeated instructions eventually led to widespread adherence," he said.

While these two interventions improved the weight monitoring indicator in CAF, the question of how

to reach people with TB who couldn't reach health centres still remained. And to address this issue, TB Champions and the STS realised, a single solution wasn't enough:

- In tribal areas, Accredited Social Health Activists (ASHA workers) were tasked with checking the weight of people with TB and reporting the data to NTEP.
- In rural and urban areas, Anganwadi Workers
   (AWWs) were engaged to monitor and report the
   weight of people with TB.
- The Tamil Nadu government's Makkalai Thedi Maruthuvam (MTM) programme, which involves door-to-door health screenings, was integrated with NTEP. MTM workers were instructed to check and report the weight of people with TB during their visits.

These measures significantly improved weight recording practices. As of the latest assessments, weight is now checked in 100% of cases in Tirupathur and 98% in the broader Vellore district.

## Vijayashanti's Story

Vijayashanti, a 22-year-old college student from a tribal village in Vellore, faced significant challenges due to her low weight and remote location. Weighing just 28 kg at the time of her TB diagnosis, her weight could not be monitored properly during the first two months of treatment. The nearest TB Unit was 24 km away, and the closest PHC was 9 km away, making regular visits difficult. After her intensive phase, when she visited the health facility for review, it was noticed that her weight had improved to 35 kg but the medication she was taking was still for the lower weight band. The TB Champions discussed with the state TB mechanism and piloted a solution with the local ASHA worker to monitor her weight weekly. This initiative allowed for timely adjustments to her medication, ensuring her successful treatment completion.

# STORY 4 Preventing TB in Children

Durg district in Chhattisgarh faced a big challenge. Despite the efficacy of INH preventive therapy in preventing the spread of TB among children under the age of five, the CAF surveys found that not all children whose family members had TB were receiving the medication. The low uptake was due to both systemic and social factors, including lack of awareness, distribution issues, and resistance from families.

The challenges included:

- Limited Awareness: Health workers and communities in rural areas lacked adequate knowledge about INH Prophylaxis for children and its importance. A significant gap in knowledge meant that even health providers like Mitanins (ASHA workers) were not fully informed.
- **Resistance from Families**: Many families, especially in rural areas, were hesitant to

- administer INH to children without visible symptoms, fearing potential side-effects or believing in traditional remedies over modern medicine.
- Prescription Gaps: Doctors at PHCs were not consistently prescribing INH, leading to a gap in its distribution. Health workers cited the absence of a doctor's prescription as a reason for not administering INH.
- Supply Chain Issues: INH was often only available in urban centres, with rural areas facing significant challenges in accessing the medication due to a lack of distribution mechanisms.
- Human Resource Shortages: The district faced a shortage of essential health staff, including TB Health Visitors (TBHVs) and lab technicians, which further hampered efforts to screen and treat vulnerable children

## **CAF CASE STUDIES**

To address these challenges and to help improve the overall TB parameters of the state, TB Champions adopted a two-pronged strategy under CAF to bring about change.

As a first step, TB Champions began a campaign at the district level. They met district health officials to drive home the benefits of early intervention and the role of INH preventive therapy. As a result, the DTO issued a district-wide guidance that all health providers must prescribe INH to eligible children under five years of age.

Next, the TB Champions organised community meetings, including at Gram Sabhas and Jan Sabhas, to educate families about the importance of INH. They also provided training to Mitanins to ensure they were informed and could advocate for INH within their communities.

Following this, TB Champions worked with the district and block level officials to deploy creative methods to raise awareness, such as jingles played on garbage collection vehicles and wall paintings in villages, to spread messages about TB and the importance of INH.

TB Champions also realised that there was a shortage of INH medication in rural areas of the district, and that the supply chain for the drugs were not efficient enough. Recognising the gap in access to INH, TB Champions began collecting INH supplies from urban centres during monthly meetings and personally delivering them to rural health centres. This ensured an uninterrupted supply of INH across the district.

The TB Champions also advocated for the recruitment of new STS staff, which helped stabilise the distribution and screening processes. They also continued to support NTEP staff by conducting home visits, ensuring proper contact tracing, and following up on INH administration.

Through persistent advocacy and education, the TB Champions have also built trust within the community and established strong partnership with officials, helping to overcome resistance to modern medical interventions.

The concerted efforts of TB Champions, combined with enhanced awareness and improved supply chain management, led to a significant increase in the uptake of INH in the district.

## Success Story: Overcoming Family Resistance in Danda Village

In the village of Danda in Durg district, Chhattisgarh, a family was highly resistant to administering INH to their children. The family, which included two children under five years of age, was initially dismissive of TB Champions' efforts, refusing to even engage in conversation about preventive therapy. TB Champions made multiple visits to the household, bringing along health officials like the STS and even a doctor to explain the importance of INH. After persistent efforts and clear communication about the safety and necessity of INH, the family finally agreed to administer the medication to their children.



Every month, I wait for TB Champions Sandhya and Nirmal, who are attached to my TU, to come and start the CAF process in the field. Initially I was a little hesitant to share any details with them. But over time, after seeing how people with TB respond to their peer supporters, my trust and confidence in the quality improvement process they follow through CAF has been fully and firmly established.

#### Ms. Alka Tirkey

Senior Treatment Supervisor, Gumla, Jharkhand

# Achieving Excellence in TB Care and Services

The AETBCS curriculum was designed by REACH as part of the ALLIES project as an integral part of CAF. The two-day AETBCS training was aimed at building the capacity of healthcare providers to work closely with communities to improve the overall quality of care and services. It sought to equip healthcare providers with the basic concepts and skills required to adopt people-centred approaches while caring for people with TB. The states nominated participants for the first set of trainings.

The objectives of the training are delivered through four modules:

- Listen: To engage with people with TB, their families and communities through active listening such that the person with TB feels respected, attended to, and is satisfied with their visit.
- Respect: To institute a rights-respectful and efficient work culture in the health facility and to set personal standards of ethical and professional excellence.
- Ally: To establish effective partnerships between self, facility and community, and educate people with TB and affected communities.
- Achieve: To articulate powerful Mission statements for their own TB Units to achieve the goal of TB elimination by 2025.

66

It is essential that all NTEP staff treat people with TB and their family members in a respectful manner. Excellence in TB care can only be achieved when each staff member is technically sound and compassionate about every person with TB. Such trainings will help bridge gaps and make services more person-centric and help us achieve the target of TB elimination.

#### Dr. Prasanta Kumar Hota

Additional Director, Public Health (TB) cum State TB Officer, Odisha



Games and group work encouraged the participants to reflect and plan how they could build a relationship with the community and stakeholders, and work in mission mode as productive professionals.

Overall, 991 NTEP officials and Community Health Officers (CHOs) were trained on the AETBCS curriculum. Feedback from the participants revealed a positive impact on knowledge, attitude and practice of soft skills among the trained healthcare personnel.

#### **Training of Trainers on AETBCS**

A two-day national-level training of trainers (ToT) on AETBCS was held in February 2024 with the following objectives:

- Creating a pool of competent and well-equipped state-level NTEP trainers with necessary skills, knowledge and understanding to deliver impactful training sessions for the district NTEP officials or other district-level healthcare providers.
- Scaling up and integrating the AETBCS training in existing Government mechanisms.

38 state-level NTEP officials and WHO Consultants from 16 States participated in the ToT.

SECTION



The ALLIES project empowered the TB Champions to facilitate holistic, person-centred care to people with TB and their families. REACH designed and piloted the TB survivor-Champion model as part of the USAID-supported TB Call to Action project (2016-2020). With the ALLIES project, in addition to expanding the number of trained TB Champions, several new trainings were designed to improve the knowledge and skills of TB Champions.

## **Trainings Undergone by TB Champions**

#### From TB survivors to TB Champions

The first step towards the capacity building of communities was REACH's flagship training curriculum for TB survivors to turn them into empowered TB Champions. A total of **1,431** TB survivors were trained as TB Champions through district and state-level workshops across 15 districts during the tenure of the ALLIES project.

The model has formally been adopted by the NTEP and is being scaled up across the country. REACH provided technical support to NTEP to develop and roll-out a digital version of the curriculum. Alongside, support was provided to states to enrol new survivors in the training, and expand training beyond project districts. A total of 1,226 TB survivors completed the online training modules.

# Training on rights-based approaches to TB and Health

A total of **994** TB survivors and Champions were provided with two-day training on rights-based approaches to TB and Health to develop an understanding of the rights of people with TB, ethical issues around TB-related stigma and discrimination, and information about TB diagnostic and treatment services among them.

#### **Data for Action**

Learning about some key fundamental concepts to better interpret data and design effective advocacy was essential to add value to the work of TB Champions. The two-day Data for Action training helped the **126** TB Champions understand the important concepts of NTEP including notification

rate, sputum examination rate, prevalence, incidence, missing cases and treatment success rate, among other aspects.

#### TB and disability

Given the linkages between TB and disability, **228** TB Champions were trained to understand the nuances of disability, with a particular focus on how they could help people with disabilities and address the stigma faced by them. They were also oriented on the provisions of the Rights of Persons with Disabilities Act, 2016 and the various social welfare schemes available for people with disabilities.

Following the training, TB Champions supported many people with TB and disability to apply for and receive a disability certificate. They also mobilised local donors and facilitated additional nutrition support for them, in addition to providing needbased counselling and treatment follow-up support to people with TB and disability.

#### **Gender sensitisation**

The National Framework for a Gender-Sensitive Approach to TB in India is a comprehensive strategy under the National Strategic Plan for TB Elimination (2017-25), which elucidates the gender dimensions of TB and also illustrates gender-responsive actions at

A TB survivor who completes the 'From TB Survivors to TB Champions' training and is willing to work in the community is referred to as a TB Champion.





the community level. Over 140 TB Champions were sensitised on the gender dimensions of TB as part of the ALLIES project. The training sensitised TB Champions on concepts related to sex and gender, and oriented them on identifying gender-responsive actions that would support their activities and the National TB Elimination Programme. In every state, trainers from the transgender community were part of the facilitation team and led sessions on the gender spectrum.

Following the training, TB Champions reached out to non-governmental organisations (NGOs) working with the transgender community and organised camps in Chhattisgarh and Tamil Nadu. They supported the community in receiving their Triteeya Ling card that identifies them as transgender. In addition, they also held discussions with the Department of Social Welfare to ensure welfare coverage for transpersons.

# The Future Looks Brighter Now

Anjan Raut, a 45-year-old daily wage labourer from Chakulia village in Gobind block of Mayurbhani district in Odisha, was diagnosed with brain TB in 2019. Around a month after commencing treatment under a private physician in Cuttack, he began experiencing numbness in his limbs. Subsequent rounds of medical consultations, MRI scans and medication for over a year did not show any substantial improvement. Therefore, forced by depleted savings and mounting debts, being the sole breadwinner for his family, he chose to discontinue treatment.

In 2020, on a follow-up visit to village Chakulia, TB Champion Geeta Behera visited Mr. Raut's residence. In her conversation with his elder brother. who was also diagnosed with TB, she learned about Mr. Raut's brain TB diagnosis and his deteriorating condition. He was unable to walk and his family was in a dire financial situation.

Geeta approached the local Sarpanch, Mr. Amit Marndi (Khuntapal Gram Panchayat), and apprised him of Mr. Raut's medical situation and his family's financial hardships. The Sarpanch facilitated the process of obtaining a disability certificate for Mr.

Raut. The TB Champion also rallied support from the Sarpanch to provide additional nutritional assistance to Mr. Raut's family. The newfound assistance helped Mr. Raut re-commence his treatment. He is now on the path to recovery. Geeta continues to inspire and encourage both him and his brother to ensure that they receive comprehensive treatment and care.

In July 2023, Network members of the Mayurbhani District Chapter of the Kalinga TB Survivors Network (KTSN) connected with Mr. Raut's family and provided him support to alleviate his financial problems. All the network members contributed money from their own pockets and opened a small grocery shop in front of Mr. Raut's house, which could be managed by the family. It was inaugurated on July 25, 2023 by the District TB Officer of Mayurbhani, in the presence of other NTEP officials, the Sarpanch, District Strategist and the network members. The network members have also linked the family to the Pradhan Mantri Awas Yojana and a new house is being constructed for them. Today, Mr. Raut's wife manages the shop and the family has found a new ray of hope.

## TB Champions Making a Difference in the Community \_\_\_\_

#### Spreading awareness about TB

Through the five years of the ALLIES project, numerous opportunities were created for and by TB Champions at the international, national, state, district, sub-district levels to share their personal experiences of TB, as well as challenges faced by TB-affected communities in general.

They used the platforms of key Day Observations, including on World TB Day, World Health Day, International Day of the Girl Child, Mothers' Day, World Environment Day, Menstrual Hygiene Day, World No Tobacco Day and International Yoga Day, to strengthen public understanding on TB and related dimensions. These initiatives encompassed a range of activities such as community awareness meetings, rallies, health camps, pledge taking ceremonies and media engagement programmes, and were organised in coordination with local NTEP teams.

#### **Outreach to local decision-makers**

TB Champions identified various community groups in their local areas, oriented them on TB, and sought their partnership in raising awareness and strengthening support mechanisms for the TB-affected community to create an enabling space for discussions on TB and hygiene at the individual and community levels. They held meetings with Self-

help Groups (SHGs), NREGA workers, at schools and with the Deputy Commissioner of the Employment Office (in Durg) to discuss how they could join the movement and conduct anti-stigma campaigns in their own spaces.

#### Focus on vulnerable communities

TB Champions prioritised outreach to specific groups who are particularly vulnerable to TB, including people with co-morbidities, people working in hazardous environments, and those who live in isolated areas, among others. They conducted education sessions with pregnant women, lactating mothers, senior citizens, people living with HIV, people living with leprosy and young people, among others. They explained the symptoms of TB at these meetings and also elaborated on where to go for

In Durg, Chhattisgarh, TB Champions also sought approval from the Supela Municipal Corporation Commissioner, and successfully displayed TB-related videos on government LED displays at prominent public places.





#### Strengthening community structures within NTEP

Through the project period, TB Champions actively participated in State and District TB Forum meetings, formation and review meetings of Jan Arogya Samiti, Panchayat-level review meetings, Gram Sabha meetings, Block Health Assembly Meetings, Viksit Bharat Sankalp Yatra programmes, Aapki Sarkar, Aapke Dwar programme and the Rashtriya Kishor Swasthya Karyakram programme.

REACH developed a TB Forum Toolkit including a Facilitators' Manual, a Workbook and a short film, which was officially launched by the Central Tuberculosis Division (CTD) in February 2024. The short film was subsequently screened at TB Forum meetings and helped members understand how an ideal TB Forum meeting ought to be conducted.

diagnosis and treatment. Emphasis was placed on good nutrition for better immunity and protection from TB. Old age homes, drug de-addiction centres and prisons were visited to talk to the residents and inmates about TB.

TB Champions supported the NTEP in Active Case Finding (ACF) campaigns, Interferon Gamma Release Assay (IGRA) testing camps, Mobile



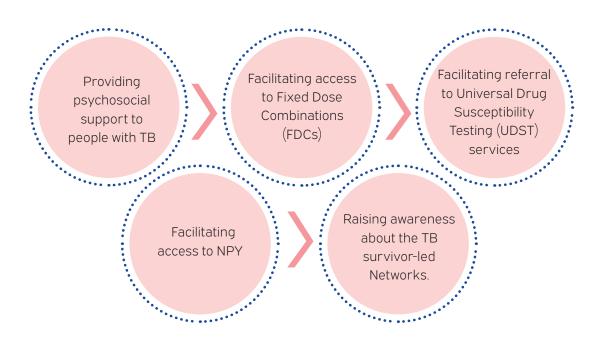
I feel proud that I am able to serve my community as a TB Champion. My work won't stop. I will keep supporting people with TB and the affected community, looking after their needs and providing linkages to services.

Rajkumar Mahato
TB Champion, Ranchi

Diagnostic Unit Camps (Tamil Nadu), and paediatric health camps to screen and identify presumptive people with TB so that they could receive timely diagnosis and treatment, thereby reducing transmission within their communities. Home visits were conducted, community participation was mobilised, X-ray examinations and sputum tests were facilitated, and people with symptoms were referred for testing, with the TB Champions often accompanying them to the nearest health facilities and supporting them through the entire process.

# Providing support to people with TB seeking care in the private sector

Over 50% of people with TB in India seek care in the private sector. A pilot intervention was designed to extend peer support and provide treatment literacy and other services through TB Champions to people seeking care in the private sector, where a few mechanisms are in place for psychosocial support. The pilot was implemented in Raipur, Chhattisgarh and Trichy, Tamil Nadu by 7 trained TB Champions. These TB Champions focused on:



## As a result of the pilot

**780** people with TB, on treatment in the private sector, were provided with psychosocial counselling

**25%** of people interested in NPY, who had not submitted their bank details for NPY were facilitated by the TB Champions through collection and submission of account details to the NTEP for NPY payment.

Only **68%** of people with TB had received the Catridge-Based Nucleic Acid Amplification Test (CBNAAT) test at the time of their interview. TB Champions facilitated NAAT testing for an additional **13%** of people with TB.

# **Community Response to COVID-19**

Through 2020 and 2021, the ALLIES project empowered the TB Champions with knowledge and skills, who then reached out to educate their communities about COVID-19, promoted COVID-appropriate behaviours, and encouraged vaccination.

### **Communications skilling of TB Champions**

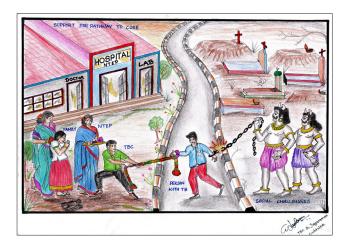
As a first step, TB Champions were trained on various communication skills through an online training package in Hindi, Odia and Tamil. More than **80** TB Champions were mentored over a threemonth period to develop high-quality products on TB, which they used to sensitise their communities.

TB Champions were trained to be skilled communicators, equipping them with the skills to convey critical information on TB to multiple audiences, through multiple mediums, including wall writings and paintings, banners, impactful slogans, as well as photographs and videos centred around TB.

### Interactive Flipbook on TB and COVID-19

In response to the COVID-19 pandemic and its impact on the communities, a flipbook was developed with information on airborne diseases like TB and COVID. The flipbook was translated into Hindi, Odia and Tamil, and widely used for community education.





### Social media creatives

A total of **13** social media creatives were developed in Hindi, Odia and Tamil. These creatives reached a total

of **3,947** people directly during the period of May 28 to June 27, 2020. A3 size posters that summarised the messages for TB Champions and people with TB were also printed and shared with the states.

### Learn to Lead series

The 'Learn to Lead Series' was a series of curated, designed social media messages shared over WhatsApp to add to the knowledge base of TB Champions who were members of the network. They were developed with the intention of encouraging TB Champions to share these messages and create awareness among the TB affected community. Developed in three languages – Hindi, Odia and Tamil – they were released to the network every Monday and Thursday.

# TB Champions recognised for their exceptional commitment and contribution to a TB-free India

On March 19, 2024, USAID and NTEP organised the TB Conclave: Commitment for Collective Action. At the conclave, TB Champions engaged in the ALLIES project were recognised for their work for TB elimination in their respective areas.

TB Champions were recognised:

- Binay Patra from Odisha for pioneering inventive and imaginative TB education strategies
- Dhaneshwari Yadav from Chhattisgarh for her efforts to challenge and dispel the stigma associated with TB
- D. Sangeetha Jhansirani from Tamil Nadu for mobilising support and resources from

local influencers and communities for people with TB

 Anjana Merry Toppo from Jharkhand for offering compassionate peer counselling and psychosocial support to the TBaffected community.

The TB Champions received their awards from Dr. Atul Gawande, Assistant Administrator for Global Health, USAID.

The Mayurbhanj district chapter of Kalinga TB Survivors Network, Odisha was recognised for being a force of change for TB-affected communities by advocating for their rights.







**REACH-ALLIES'** contribution has been instrumental in bringing the state one step closer to achieving a TB elimination status. The project empowered TB survivors, transforming them into Champions who supported treatment adherence and facilitated nutritional support for people with TB.

### Dr. Asha Frederick

Additional Director of Medical & Rural Health Services (TB) & State TB Officer, Tamil Nadu

**TB Champions' contribution** in motivating people with TB, participating in community awareness programmes and facilitating nutrition support has been tremendous. They are enablers, supporting even as Treatment Supporters.

Dr. S. Savithri District TB Officer, Trichy The efforts of the ALLIES project to facilitate community involvement are a vital step towards elimination of TB in the country. The project has been instrumental in training smart TB Champions, sensitising elected representatives and even organising nutritional support programmes.

Dr. Karunakaran District TB Officer, Cuddalore

# Strengthening TB Survivor-led Networks

4

SECTION



Survivor-led networks play a critical role in advocating on behalf of TB-affected communities, including people with TB, TB survivors and their families. These networks provide the TB Champions with a sense of collective identity and serve as platforms through which members can expand their impact and collaborate with various stakeholders for efforts to end TB.

# Strengthening of State Level Survivor-led Networks

To create powerful advocates as key change agents or community enablers who can undertake strategic advocacy

Financially Sustainable routes for Networks Organisationally Sustainable Networks, with able leadership and informed membership, through better local representation at District and Sub-District level

Income generating activities for network members

Leadership training for Governing Body Knowledge building sessions of members Formation of district level Chapters of State Networks

# TB Survivor-led Networks Formed and Strengthened\_

TB survivor-led networks in Chhattisgarh (TB Mukt Chhattisgarh Foundation – TBMCGF), Jharkhand (TB Elimination from Jharkhand) and Odisha (Kalinga TB Survivors Network) were formed during the USAID-supported TB Call to Action Project. TB Free Tamil Nadu Survivor Led Network was formed during the ALLIES project in 2021.

Over the years, the networks have grown in strength with an expanding membership. They are now independent registered entities, with district chapters in select districts. Tamil Nadu network has 2,425 members, Odisha has 1,300+, Jharkhand 770+ and Chhattisgarh has 600+ membership.

The ALLIES project supported these networks to expand and establish stronger governance

mechanisms. Regular knowledge building sessions were held for all members and members provided with NTEP updates and information on TB care and prevention in the context of COVID-19, etc. In addition, meetings were also organised specifically for governing body members. Special trainings on leadership skills, income generation activities, advocacy and several other relevant aspects were organised for network leaders. Some of them have been briefly described below.

### Leadership training

Trainings for network leaders to become empowered leaders of survivor-led networks with a robust skill set, including moral imagination, value-based decision-making, persistence, courage, authentic communication, and relationship-building.



### Organisational development and advocacy

A two-day training for network members across the four states with the objective of building their capacity to understand the importance of advocacy in TB response and how it can be an effective tool in bringing about a positive change. Participants were made to understand the concept of organisation and the vision, mission and goals for networks, and various phases of organisational development with a view to better organise the network activities for effective advocacy and providing peer support.

# Livelihood training

ALLIES project has provided network members with skill building and income generation training to foster livelihood opportunities for them. For example:

Over 85 TB Champions in Odisha have received training on sabai grass crafting, artificial jewellery making, mushroom cultivation and phenyl making. Market linkages have been established with the support of the Odisha Livelihood Mission for sabai grass products.



Uzhavan Wood Pressed Oll
The Management of the Control of the Cont

Five TB Champions in Coimbatore started a homemade cold-pressed oil-making unit with the support of BOSCH-CSR unit which made a contribution of INR 2.5 lakhs in October 2023. The TB Champions produce coconut, sesame and grapeseed oils, generating an average monthly income of INR 2,500, of which 5 percent is contributed to the District Level Network.

The Raipur chapter of the Chhattisgarh network bought an e-Rickshaw to earn some rental income, which could be distributed among the network members proportionately. The first e-rickshaw was formally introduced in February 2024. It is being operated by a TB survivor and he contributes his income to the TBMCGF monthly. Besides, the e-rickshaw is also used to generate TB awareness.



In Balod district, TB
Champions have **started making Badi** (a local
delicacy), which is sold at
C-Mart, a store promoted
by the Government of
Chhattisgarh, to promote
local produce of the state.



In Durg district (Chhattisgarh), the District Chapter sought support from JK Lakshmi Cement to set up an **LED bulb-making enterprise**.



One TB Champion in Coimbatore started a **beauty parlour** with seed money of INR 35,000 from an NGO and is successfully running the business, earning an average of INR 10,000 per month.

In other districts, initiatives included Villupuram's jute bags, Cuddalore's nutrition powders, and Krishnagiri's Balkoa (a sweet recipe). Sales are conducted locally and products are exhibited at government meetings and event stalls.



## Advocacy to increase Ni-kshay Poshan Yojana Support Amount

Chhattisgarh was the first state to provide nutritional support to people with TB even before NPY was launched. All people with TB are currently given INR 500 per month under the scheme. In 2022, members of TBMCGF advocated

for an increase in this amount. They requested for additional nutrition support for people with TB and as a result, the Government of Chhattisgarh agreed to provide INR 200 in addition to the INR 500 given by the Central Government.

# **Cross-learning among networks**

A two-day cross-learning and exposure visit for the TB survivor-led network members of all four ALLIES states was organised in Patna, Bihar in May 2022. The objective was to strengthen the networks' peer learning, knowledge and capacity building through direct interactions with TB Mukt Vahini (TMV), the first registered TB survivor-led network in India. A total of 25 active network members including the Network Coordinators and Governing Body (GB) members from five

networks participated in this cross-learning visit, and exchanged ideas and best practices. The discussions included the role of networks, functional aspects including documentation and maintenance of network bye-laws, Memorandum of Association, rules and regulations, and the duties and function of the Executive members in the networks. This platform also provided the opportunity for all the participants to experience the strength of networks.

# Touched by TB\_

Touched by TB, a national coalition of TB-affected communities, was formed in 2017. The ALLIES project supported Touched by TB to expand their operations to four North Eastern states (Assam, Meghalaya, Sikkim, Nagaland) and in Delhi.

During the project period, 5 state-level networks were launched, 10 district level networks formed, and more than 50 grassroots survivors were identified in partnership with the district NTEP teams. Their capacities were built on TB care and services in three-day workshops using local resource persons and CTD modules. With the help of these networks, 36 TB Champions reached out to over 12,000 people through home visits and awareness camps in Delhi, Assam, Sikkim, Meghalaya and Nagaland.



# **Leaving No One Behind**

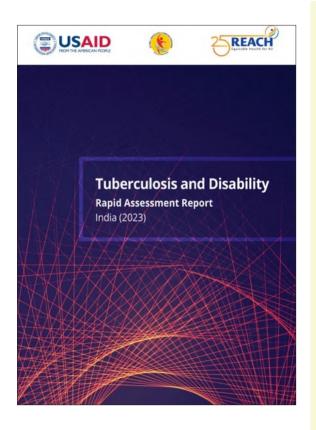


Ensuring equitable access to TB services is fundamental to achieving TB elimination. Commitment to promoting equity and inclusiveness was at the core of the ALLIES project.

# TB and Disability

The intersectionality between TB and disability, whether as a pre-existing condition prior to contracting TB or as a consequence of TB, has remained largely understudied in India. In 2022-23, REACH conducted a firstof-its-kind national-level rapid assessment on TB and disability, with a focus on three key aspects: the impact of TB resulting in disabilities (short- and long-term); how disability features in and impacts the TB care cascade; and challenges for people with disabilities (PwD) in accessing TB services.

As a follow-up to the assessment, TB Champions were trained to understand the nuances of disability, how they could help people with disabilities and address the stigma they faced (see page 21). Disability as a component was also included into the CAF tool (called Comprehensive Assessment Tool). TB Champions identified people with TB and disabilities, understood their challenges, linked them to schemes, and provided supportive services like hearing aids, etc.





# Key findings from the CAT data

Of the 13,838 people with TB interviewed, 2.7% (377) reported a disability.

Of the **377** people who reported disabilities

100 (27%) developed disability during TB treatment. Of this 100, 26 had low vision, 21 were hard of hearing, and 24 had a locomotor disability.

102 people were in the elderly age group and **5** were people with MDR-TB.

**207** required travel support, **57** required support to navigate health facilities, 39 requested support to explain disability to healthcare providers, and 23 requested support to cope with stigma.

# Empowering a Person with Disability – The Story of Rajappan

Rajappan, an elderly man from Mettupalayam GH, Karamadai TU, Coimbatore, Tamil Nadu faced a severe challenge when he was diagnosed with bone TB in his leg. This eventually led to the amputation of his leg, leaving him and his elderly wife in a vulnerable position. Rajappan was the sole breadwinner of the family, and the disability left the couple with little resources and no one to take care of them.

When TB Champion Sugashini met Rajappan while implementing the CAF tool, she put her disability to good use. "I was inspired and motivated by the training, which emphasised the rights of disabled individuals and the various government schemes available to support them," Sugashini said.

Armed with this knowledge, she immediately took the following steps to help Rajappan:

Securing a Disability Certificate
 Understanding the importance of a disability certificate, Sugashini arranged for an orthopaedic surgeon to examine Rajappan. She arranged transportation to the clinic, ensured that all necessary documentation was in place, and successfully secured the doctor's note, a crucial step in accessing further benefits. She

then applied for the Disability Card for Rajappan.

### Opening a Bank Account

Rajappan's previous bank account had been frozen due to insufficient funds. Sugashini approached the State Bank of India, explained Rajappan's situation, and convinced the bank manager to open a new zero-balance account for Rajappan, ensuring that his financial security would not be compromised in the future.

### Applying for a Disability Pension and Additional Support

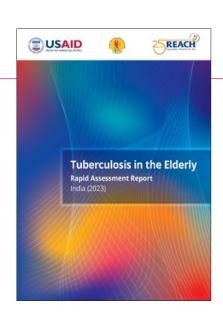
With the Disability Card in hand, Sugashini helped Rajappan apply for disability pension. She also liaised with the Department for the Welfare of the Differently Abled to request an artificial leg for him, further improving his quality of life.

Sugashini's efforts have transformed Rajappan's life. Not only did she ensure that he receive the necessary medical and financial support, but she also empowered him by helping him navigate the bureaucratic processes.

This case illustrates the significant difference that informed, motivated, and compassionate TB Champions can make in the lives of those they serve.

# TB in the Elderly\_

In 2022-23, REACH conducted a national-level rapid assessment on TB in the elderly, the first-of-its-kind in India, aimed at identifying practices and specific areas for interventions to strengthen India's response to TB in the elderly. The assessment showed that factors which most impact a person with TB's journey through the care cascade include physical vulnerabilities due to age and loss of economic independence worsened by poor linkages to financial support mechanisms. At the health system level, there are challenges for elderly people with TB at all levels of implementation - access to facilities for diagnosis and treatment, service provider capacity, and support systems.



As a follow-up to the assessment, the ALLIES project piloted a special intervention targeted towards operationalising a care model for elderly people with TB. The intervention was initiated in February 2024 in Bhubaneswar (Odisha), Bokaro (Jharkhand), Durg (Chhattisgarh) and Vellore (Tamil Nadu), and later expanded to Mayurbhanj (Odisha), Ranchi (Jharkhand), Raipur (Chhattisgarh), and Cuddalore and Villupuram (Tamil Nadu) in June 2024.

# As part of the pilot, trained TB Champions ensured

- Fast-tracking of all elderly people with TB through the diagnostic care cascade and support with prompt treatment initiation.
- Identification of specific, person-centred needs of all elderly people with TB through a comprehensive needs assessment.
- Provision of a customised package of care and support services to all elderly people with TB based on needs assessment.



A total of 3,011 elderly people were screened for TB symptoms, 468 were identified with TB symptoms, 460 supported for TB test, 50 diagnosed with TB and initiated on treatment.

Comprehensive needs assessment was conducted with 244 elderly people with TB and 130 (52%) were provided with supportive services covering various needs such as psychosocial support, transportation, existing health issues, nutritional necessities, and access to social schemes.

### TB and Gender

Throughout the project period, REACH supported NTEP to strengthen and operationalise the National Framework for a Gender-responsive Approach to TB. India is one of the first countries

to demonstrate a process to introduce gender-responsiveness at scale. The following initiatives were undertaken to operationalise the framework.



A total of 131 participants (60% women, and 40% men) including State TB Officers, state NTEP teams and WHO Consultants were trained through 5 regional-level workshops in 2022 on understanding and strengthening the gender-responsive approach to TB. At least one senior NTEP representative from 33 of 36 states and Union territories was trained. A transwoman was one of the lead facilitators in the training team.



Central TB Division constituted a Sub-committee of Experts for Gender-responsive and LGBTQIA++ affirmative actions in TB to discuss the consolidated inputs from LGBTQIA++ communities and recommend incorporation of relevant inputs into the framework. Anupama Srinivasan, Assistant Director, REACH, was a member of the sub-committee and the writing group that revised the framework. The revised Framework was launched by the NTEP on World TB Day 2024 in New Delhi.



In 2023, TB Champions from all four states were trained on TB and gender through state-level workshops, which introduced them to the gender dimensions of TB, and helped them identify community-level actions they could undertake to address gender-specific needs.

In Durg, Chhattisgarh, following the gender training, TB Champions facilitated special screening and awareness camps on TB for 300+ transpersons. At these meetings, transpersons raised the issue of identity cards needed to access social security schemes. TB Champions discussed this with the Department of Social Welfare. As a result, 153 transpersons were issued the Triteeya Ling card. The TB Champions also helped transpersons get Ration Cards and Ayushmaan Cards. In one case, a trans person was able to get a subsidy under Pradhan Mantri Awas Yojana for a new house.

# **Engaging Transgender Communities in the TB Response**

In keeping with the project's mandate to promote equitable TB services for all, transpersons and leaders from the transgender community, as well as organisations working with trans communities, were identified and included in discussions on TB in the four project states.

In 2024, roundtable discussions were held in all four states, in coordination with NTEP and State AIDS Control Societies. The discussions saw a

participation of 51 NGOs (3 in Chhattisgarh, 10 in Odisha, 14 in Tamil Nadu and 24 in Jharkhand). The roundtable discussions gave a detailed overview of the TB disease, its burden in the state, the NTEP structure, vulnerabilities that increase risk of TB infection, and delved into understanding the challenges faced by the transgender community in accessing TB services, current activities undertaken by the NGOs and identifying strategies for engaging the transgender community in the TB response.



# **Differentiated Care Model (DCM)**

A DCM was implemented in 3 Treatment Units (TUs) of Odisha; Betnoti, Kaptipada and Rangamatia and 14 Nakshatra Centres in Chennai in Tamil Nadu to deliver person-centred care to address different vulnerabilities. Trained TB Champions screened

2,091 newly TB-diagnosed people of 18+ years of age, with their consent, for a combination of clinical and social vulnerabilities: alcohol use, smoking, malnourishment, migration, living alone and anaemia (in Odisha only).

# Key findings of the screening

### Number of people screened

In Odisha, a total of **550** people with TB were screened for different kinds of vulnerabilities, including **33%** women.

In Tamil Nadu 1,541 people with TB were screened, with 45% women.



### Vulnerabilities experienced

In Odisha, **94%** of men reported at least one of the six vulnerabilities and **91%** of women reported having at least one vulnerability.

In Tamil Nadu, 77% of men reported having at least one of the five vulnerabilities and 66% of women reported having at least one vulnerability.



### Malnutrition\*

In Odisha, **79%** of men and **83%** of women were found as malnourished. **99%** of malnourished people had a BMI score of less than 18.5 kg/m<sup>2</sup>.

In Tamil Nadu, **52%** of men and **56%** of women were found as malnourished. **43%** of malnourished people had a BMI score of more than 25 kg/m<sup>2</sup>.



# Alcohol use

In Odisha, about **65%** of men and **23%** of women reported alcohol use.

In Tamil Nadu, 30% of men and less than 1% of women reported alcohol use.



### Anaemia

In Odisha where anaemia testing was done, **55%** men and **53%** women were observed with anaemia.



### **Migration**

In the tribal setting of Odisha, migration was reported by less than 1% of the screened people.

In Tamil Nadu, 18% of men and 17% of women reported migration as a vulnerability.

Chennai being a metro city attracts a lot of people for employment and other reasons.



<sup>\*</sup> People with a BMI score of less than 18.5 kg/m² and more than 25 kg/m² were reported as malnourished.

# Efforts made to link those identified with vulnerabilities to specialised care

### People with alcohol use and smoking

Linked to **de-addiction counselling** in Chennai

Provided counselling by a medical officer in Odisha



# People reporting malnutrition (in both states)

Linked to expert **nutrition counselling** 

A **diet chart** provided in the local language

Wherever possible, additional nutrition support provided through linkage to a Ni-kshay Mitra



# People with anaemia (in both states)

Linkages facilitated for access to free Iron and Folic Acid (IFA) tablets from public health facilities



### People who were migrating (In Odisha)

Support with treatment literacy provided in the local language

**IEC material** provided for after use

Psychosocial counselling provided for treatment adherence

For those willing to seek care from a different area, transfer out process facilitated



### People who were living alone (in both states)

Psychosocial counselling provided

Those in need linked to additional nutrition support



# **Mobilising Multisectoral Action**



In keeping with its goal of creating an enabling environment for TB elimination, the ALLIES project has accelerated multi-stakeholder participation at the national, state, district and community levels through sensitisation of various key stakeholders and decision-makers, including Elected Representatives, industries and the media. Through the project period, 2,287 Elected Representatives were sensitised and 1,046 engaged; 94 industries signed on to undertake TB-related activities, and journalists were sensitised through 14 media roundtables. In addition, 58 Media Fellows wrote over 180 news stories on various aspects of TB in leading print and electronic media.

# Sensitisation and Engagement of Elected Representatives

The effort to create an enabling environment with empowered community advocates was undertaken with Elected Representatives. TB Champions engaged with them at all levels – from Panchayats to state legislatures – and sensitised them on the enormity and scale of the TB burden, the profound personal ramifications faced by those affected, and the potential contributions that could be made by the Elected Representatives.

ALLIES project also supported the Pradhan Mantri TB Mukt Panchayat initiative by facilitating state, district and block-level workshops with government functionaries and PRI members, orienting them on the indicators for creating TB-free Panchayats and supporting them in subsequent community-level activities.

Through their sustained efforts, TB Champions inspired Elected Representatives, and Panchayati Raj representatives to:



Facilitate additional nutrition support to people with TB as Ni-kshay Mitras



Extend access to social security benefits like Pradhan Mantri Awas Yojana



Facilitate local transportation to and from medical facilities



Personally interact with people with TB using the CAF tool



Ensure display of TB-themed artworks outside Panchayat offices



Participate actively in TB awareness programmes



# Advocacy with PRI members for nutritional support and housing benefits to people with TB in Durg, Chhattisgarh

Mr. Tekram Pal (name changed), a 42-year-old person with TB, lives with his wife and two children in Patan block of Durg district, Chhattisgarh. Tekram was diagnosed with pulmonary TB early in 2024. In March 2024, TB Champion Ms. Rupershwari Yadav first interacted with Tekram during her visit to his home to fill CAF's Quality Assessment Tool. She was shocked to see the dilapidated condition of Tekram's house. His food intake and nutritional levels was also inadequate. Concerned, Rupeshwari met the Sarpanch of Naradi Gram Panchayat Mr. Lalit Singh and

discussed additional nutritional support for Tekram, and other needy people with TB. She also urged Mr. Singh to link Tekram's family with the housing scheme and supported Tekram in submitting the necessary documents to the CEO of the District Panchayat, a nodal officer for the housing scheme. As a result of these efforts, Tekram was given additional nutrition support by the Sarpanch for the remaining 4 months of his treatment. In addition, the Sarpanch also assured full support to Tekram for housing scheme benefits, providing a temporary house for his family.

# Sensitisation of Industries on Employer-Led Model for TB Care and Services

A strategic and collaborative approach was undertaken to engage with industries through the Employer-Led Model (ELM), an approach where the employers are responsive to the needs of people with TB and their family members, and promote

policies inclusive of their needs. Due to these efforts, not only did leading industries like Steel Authority of India, Usha Martin Limited, Hindalco and BOSCH became Ni-kshay Mitras but also provided support livelihood initiatives for people with TB.



# Workplace Policy on TB and its Co-morbidities including Occupational Lung Diseases officially launched in Jharkhand



On July 12, 2023, Jharkhand became the first state in India to launch a workplace policy for people with TB. The Jharkhand Workplace Policy on TB and its Comorbidities including Occupational Lung Diseases was officially launched by the

Honourable Health Minister, Government of Jharkhand Shri Banna Gupta and Honourable Labour Minister, Government of Jharkhand Shri Satyanand Bhokta at a ceremony held at the Jharkhand Mantralaya.

REACH supported in the drafting of the policy. The Jharkhand Assembly Cabinet gave its approval to the policy on December 31, 2020 and the Gazette publication for the policy was released on December 16, 2021. Following the

cabinet approval, industries such as Jindal Steel & Power Limited (Ramgarh, Jharkhand) and Usha Martin Limited (Ranchi, Jharkhand) signed a Letter of Intent (LoI) with the District Tuberculosis Cell for the TB-free workplace policy. In Bokaro, Gumla and Ranchi, 58 industries were sensitised out of which 36 signed LoIs with the respective District TB Cells (DTCs).



REACH's efforts have helped in drafting the Jharkhand Workplace Policy. The feedback provided by people with TB has supported NTEP in delivering better care and services. All of this is going to make a positive impact on TB elimination in Jharkhand.

**Dr. Kamlesh Kumar** State TB Officer, Jharkhand

# **Engaging the media**

In India, TB is underreported and misconceptions are widespread. In 2009, REACH began working with the media, specifically print journalists, to improve the quality and frequency of media reporting on TB. Over the past 15 years, REACH has actively collaborated with the mainstream media through structured engagement interventions such as Media Fellowships and Media Awards to recognise excellence in TB reporting, and state- and district-level media roundtable discussions.

### Media Fellowship Programme

The REACH Media Fellowship Programme for Reporting on TB is a flagship intervention, in keeping with REACH's mandate to engage the media for consistent, high-quality reporting on TB. Special emphasis was laid on engaging journalists reporting in local languages to ensure that it reaches the last mile, fostering a more inclusive and impactful outreach on TB.

Meticulous selection of Media Fellows is done every year, followed by an orientation which provides them valuable insights on the science of TB, the operations of the NTEP, TB-related co-morbidities, DR-TB, and the challenges faced by those living with the disease, among other topics. This strategic approach yielded a consistent output of at least 50 high-quality TB feature articles annually, while also nurturing a network of trained Media Fellows who continue to write about TB.

Some of the stories covered topics such as the dangers of incorrect TB diagnosis, the rising risk of DR-TB, and the innovative delivery of sputum samples by postmen in Jharkhand. Also covered were topics related to the impact of TB on women's health, TB in tribal areas, mental health issues among people with TB, and non-communicable diseases (NCDs) as risk factors for TB.



# State Level Media Roundtable World TB Day 2023 YES! WE CAN END TB Date: 214-038973 | Vernue: Statement International Control of the Statement Cont

### Media awards

Instituted in 2010, the REACH Media Awards highlight the vital role played by the media in informing the public and decision-makers about TB prevention and care. Journalists working for any publication in India and independent journalists were eligible to submit their TB-related stories in two categories: English and Local Language. Through the ALLIES project, awards were presented to winners in 2022 by Ms. Veena Reddy, Mission Director, USAID/India and Dr. Rajendra P. Joshi, then DDG-TB, Central TB Division, Ministry of Health and Family Welfare (MoHFW), Govt. of India, and in 2023 by Dr. Atul Gawande, Assistant Administrator, USAID.

### **Media roundtables**

An integral mandate for REACH is to elevate media awareness and engagement in India's TB response by amplifying coverage and public understanding, besides galvanising community support to end TB. A total of 14 roundtables were organised by the ALLIES project and **416** journalists were sensitised on TB. The roundtables brought together health officials with journalists, provided journalists with updated information on TB, and encouraged ethical reporting on TB.

# Youth-led Campaign to End TB

A youth-led campaign to end TB in India – 'Yes, We Can End TB' – was launched on January 12, 2024 - National Youth Day. The campaign focused on activities around and ahead of World TB Day, observing the day on March 24, 2024 and culminated on April 07, 2024 - World Health Day. As part of the campaign, young TB survivors and TB Champions (18 - 29 years of age) led grassroot-level activities sensitising fellow youths and other stakeholders on TB and engaged them to work together.

A virtual event was organised with **150+** youth TB Champions from across India in January 2024 on the occasion of National Youth Day. At the event, Dr. Nishant Kumar, Joint Director, Central TB Division, MoHFW, Government of India and Ms. Amrita Goswami, Development Assistance Specialist, USAID/India officially launched the campaign.

Subsequently, regional WhatsApp community groups were formed for young TB survivors and TB Champions across India to share updates of the activities they conducted. TB Champions conducted one specific type of activity each month and



ensured focused outreach to as many youths as possible in their areas.

More than **100** Youth TB Champions from all the ALLIES states reached out to a diverse array of **13,107** people in the youth/adolescent population and over **4,000** people above 30 years audiences through **150+** activities ranging from TB awareness, slogan and poster creation to art workshops, quizzes and ACF. These included school and college-level engagements, community meetings, programmes at local markets and slum areas, and even integration into sports events.

# **Events and Key Highlights**

## **TB Champions Conclave**

August, 05 - 06, 2024, New Delhi

A national level TB Champions Conclave was organised in Delhi to highlight and share the contributions of TB Champions to the TB programme in India, strengthen their knowledge and understanding on new technical developments in the NTEP, and



to facilitate sharing and cross-learning of effective strategies. The Conclave was attended by state-level NTEP representatives and 50 TB Champions from 10 states.

# TB Centrestage Discussion on Community-Led Monitoring of TB

June 20, 2024, New Delhi

A discussion on Community-led Monitoring (CLM) of TB was held to understand and reflect on different CLM models and their successes, identify key elements of an effective CLM model for TB, and collectively outline a vision for CLM for TB in India. About 30 participants from different partner organisations, officials from Central TB Division, Government of India, officials from USAID/India, and TB Champions from several states actively participated in the discussion.



# TB Centrestage Discussion on TB in the Elderly, and TB and Disability

May 30, 2023, New Delhi

REACH, in collaboration with the Central TB Division, MoHFW, Government of India and USAID, brought together over 60 government and non-government stakeholders, including TB survivors and Champions, in Delhi for a TB Centrestage Discussion on TB in the Elderly, and TB and Disability. Two national-level rapid assessments conducted by REACH on 'Tuberculosis in the Elderly: A Rapid Assessment in India' and 'Tuberculosis and Disability: A Rapid Assessment in India' were formally released at the event.



# **TB Champion Conclave**

March 23, 2023, Varanasi

On the eve of World TB Day 2023, a national-level conclave was organised for and by the TB Champions of India in Varanasi, in



collaboration with the Central TB Division, USAID and the Stop TB Partnership. Over 150 delegates, including 50 TB survivors and Champions from across the country, participated in the Conclave, which highlighted the struggles of people affected by TB, efforts to build bridges between the community and health system, and the transformative change from community engagement to community ownership for TB elimination.

Two publications developed by REACH – CAF in Action and TB Champion Empowerment Index – were released at the conclave. Alongside, The Varanasi Statement by TB Champions, a 16-point collective vision that captures the essence of community mobilisation and commits to reducing suffering and saving lives of people with TB was also released.

# TB Centrestage Discussion on Building an Equitable and Inclusive Response to TB in India

### December 2022, Chennai

TB Centrestage discussion was held in Chennai, focusing on recognising and acknowledging the importance of incorporating an equitable, inclusive approach to TB in India, and to understand progress made in adopting equitable approaches to TB. It was attended by over 40 experts working in the field of TB, public health, law, media and related fields. The meeting aimed to recognise and acknowledge the importance of incorporating an equitable, inclusive approach to TB in India.



# **TB Centrestage**

### March 2022, New Delhi

The annual TB Centerstage Discussion on Investing to End TB: A Community Led Response to Save Lives was organised.
On this occasion, Dr. Rajendra P. Joshi, Deputy Director General (DDG)-TB, Central TB Division, Government of India, formally released the 'Art to End TB Stigma' compendium featuring artwork by TB Champions along with a series of short films developed by REACH. Over 60 TB Champions from Bihar, Chhattisgarh, Gujarat, Himachal Pradesh, Jharkhand, Madhya Pradesh, Maharashtra, Odisha, Uttarakhand, Rajasthan and Tamil Nadu participated in the event.



# **TB Centrestage**

### March 2021, New Delhi

A TB Centrestage Discussion was conducted on the subject –
Forging a Community-led Response to TB. The meeting was
structured as a series of short panel discussions to gather feedback

Forging a Community-led response to TB
A TB Centrestage Discussion

Organical by Forth and University, in association with DD

Downward TB

Organical Community Commun

on CAF for Improved Quality of Care and Services; vision of CAF; the evolving role of a TB Champion; and voices from the community and TB Forums for strengthened community engagement.



# **Empowerment Evaluation**

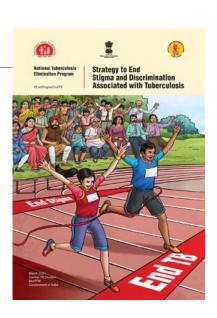
The ALLIES project collaborated with Prof. Dr. David Fetterman, Father of Empowerment Evaluation, to introduce principles of Empowerment Evaluation, with support from USAID. The objective was to build local evaluation capacity, including among communities. The empowerment evaluation focuses on helping communities monitor their own programme progress and evaluate outcomes. A 3-step empowerment evaluation approach was used to help communities:

Prof. Fetterman led several virtual sessions for REACH team and with TB Champions, before facilitating in-person sessions in India in June 2024.

- Establish their mission (or purpose)
- 2. Take stock or assess current performance
- 3. Plan for the future (specifying goals, strategies to achieve goals, and credible evidence).

# **Development of Stigma** Strategy Document

Through the ALLIES project, REACH supported the NTEP in the development of the 'Strategy to End Stigma and Discrimination associated with Tuberculosis'. REACH was a member of the working group that helped draft the strategy document and also supported in the design and dissemination process.



### **USAID Team Visits to ALLIES Sites**

## Dr. Genessa Giorgi, Health Attaché, U.S. Embassy in India visited Raipur, Chhattisgarh

Dr. Genessa Giorgi, Health Attaché, U.S. Embassy in India visited LON ALLIES site in Raipur, Chhattisgarh on April 05, 2024 and had an interactive meeting with TB Champions and the ALLIES team.

## US Consul General Hyderabad visited Bhubaneswar, Odisha

Ms. Jennifer Larson, US Consul General in Hyderabad, and Mr. Frank P Talluto, Pol/Econ Chief, US Consulate Hyderabad visited the LON ALLIES Project site in Bhubaneswar, Odisha on December 08, 2023 and interacted with the ALLIES Odisha team and TB Champions.

# USAID Asia's Senior DEIA Advisor visited Bhubaneswar, Odisha

Ms. Kathryn Booker-Veloz, Senior DEIA Advisor, USAID Asia and her team including Mr. Aaron Schubert, Control Officer, Mr. Brian Holler, Health Foreign Service Officer, and Ms. Martha Van Lieshout, Senior Development Outreach and Communications Specialist visited ALLIES project sites in Bhubaneswar, Odisha on November 08, 2023.

## US Consul General Mumbai visited Raipur, Chhattisgarh

On October 10, 2023, Mr. Michael Hankey, US Consul General Mumbai along with his team Ms. Ayesha Khan, Political Specialist, US Consulate, Mumbai and Dr. Neeta Rao, Senior Health Lead, USAID/India



visited ALLIES project sites in Raipur, Chhattisgarh and interacted with the ALLIES team and TB Champions on the changes in the TB programme since the implementation of the community engagement initiative.

### USAID Mission Director's visit to Bhubaneswar, Odisha

On April 27, 2023, Ms. Veena Reddy, Mission Director, USAID; Ms. Elaine Li and Ms. Martha Van Liesht, Program Support Office; and Ms. Amrita Goswami, Development Assistance Specialist visited the LON ALLIES Project site at Bharatpur Community Centre in Bhubaneswar, Odisha.

### **USAID Team visit to Bhubaneswar, Odisha**

A delegation from USAID India including Ms. Sangita Patel, Director Health Office, and Ms. Amrita Goswami, Project Management Specialist visited Bhubaneswar on October 21, 2022 to interact with TB Champions, members of Kalinga TB Survivors Network (KTSN), People with TB, and TBHV-NTEP on CAF.



# **ALLIES Team at The UNION Conference on Lung Health**

# 2020

Eight TB Champions were panelists in the 'Community Connect session on TB Champions respond to COVID-19 - Narratives from India'. TB Champions from the project states shared their role and support to communities on TB services during the COVID-19 pandemic.

### **E-poster presentations on:**

# 2021

Lessons from an integrated approach of communication skilling and community engagement pilot project in India

Improving access to TB services - Formulation of Workplace Policy on TB in Jharkhand, India Partnering with industries for TB elimination through Corporate TB Pledge

### **Community Connect Sessions**

TB Champions pilot a Community Accountability Framework Stigma assessment by TB Champions: A window to social conditioning that perpetuates stigma

### **Community Connect Sessions**

Working with ERs for TB elimination

TB-affected communities use CAF to improve quality of TB care and services

# Peer-peer engagement: Survivor-led networks supporting TB-affected communities

# 2022

Youth4LungHealth - TB Champion Chandrakala Yadav from Chhattisgarh described how they went about building smokeless chulha (stove) to help communities address indoor air pollution. TB Champion Binay Patra from Odisha, meanwhile, elaborated on community-level meetings to mobilise locally-elected representatives towards TB care and prevention.

E-poster: Building the capacity of healthcare workers towards
Achieving Excellence in TB Care and Services (AETBCS)

Oral abstract presentation: Engaging ERs for TB-Free Village Initiative by TB Champions in Tamil Nadu, India Findings from a communitybased assessment implemented by TB Champions using the Stop TB Stigma Assessment Tool to measure TB-related stigma

## **Oral presentations:**

# 2023

Community Accountability
Framework: Improving
the Quality of TB Care and
Services in India by leveraging
community action as an ally

Assessing status of anaemia as a vulnerability among people with TB in tribal setting – Experience from Odisha, India Vulnerability
assessment among
persons with TB in tribal
and urban populations
settings in India

Tapping into latent local resources for meeting additional nutritional needs of people with TB in Tamil Nadu, India

Mid-media to overcome hard-to-reach area: Generating TB awareness among tribal communities in Odisha

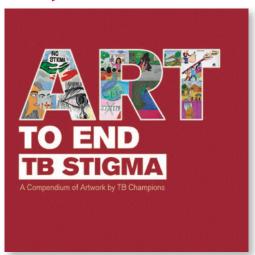
Artwork by 3 TB Champions presented at the Community Connect Art Exhibition

# **ALLIES Publications and Films**

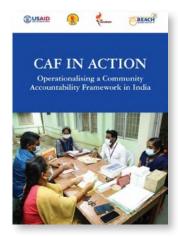
# Flipbook on TB and COVID-19

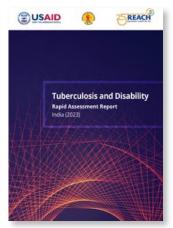


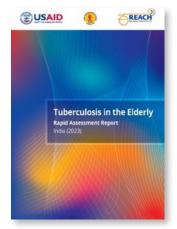
# Art to End Stigma Compendium



# **Other Publications**

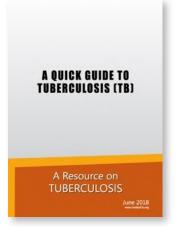












# **Bane TB Champion Animation Series**





https://www.youtube.com/watch?v=uMMrM-Ytuk4



# **COMMUNITY-LED ACTION TO END TB**

























THE ACCOUNTABILITY LEADERSHIP BY LOCAL COMMUNITIES FOR INCLUSIVE, ENABLING SERVICES (ALLIES) PROJECT



Resource Group for Education and Advocacy for Community Health (REACH)

No. 194, 1st Floor, Avvai Shanmugam Salai Lane, Lloyds Road, Royapettah, Chennai - 600014 Phone: 044-45565445 / 28132099

**Email**: support@reachindia.org.in Media Related Queries: media@reachindia.org.in



www.reachindia.org.in





@SPEAKTB



@REACHSpeakTB

All photographs in this report that feature TB Champions and/or people with TB are used with full, informed consent.