

Community based person-centered TB care by trained TB survivors under Unite to ACT project in India

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People with TB- challenges and unmet needs

- **India** contributes to **more than one-fourth of global TB burden**; ~2.4 mln notified cases in 2022.
- **Stigma**- leads to delay in access to TB treatment and/or instances of TB treatment interruptions.
- **Poor awareness** in communities, misbeliefs, misconceptions have been linked to TB related stigma and TB adherence
- The people with TB often visit multiple healthcare providers for TB care. This leads to confusion/frustration in the patients and their families due to **long TB diagnostic pathways**.
- People with TB and their families face **catastrophic expenditure** (including wage loss) during TB diagnosis and treatment.
- TB treatment focuses on clinical management; less emphasis is given to psychosocial support.



Unite to ACT project



Aim: To amplify access to person-centered support services, leveraging the lived experiences of TB survivors to drive impactful change and improve outcomes for TB patients.



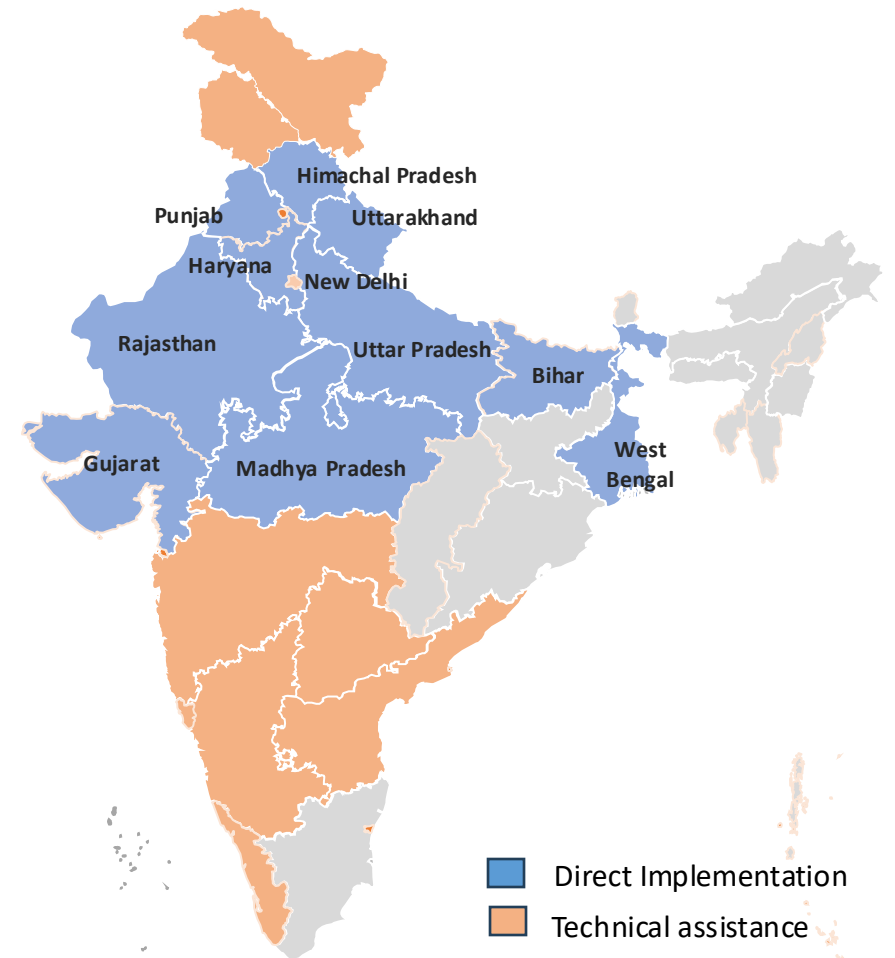
The project was implemented in 25 states/UTs during 2021-2024, in collaboration with India National TB Elimination Programme (NTEP).



Direct implementation in 11 states (82 districts)



Technical assistance was offered to 14 States/UTs (to implement person-centered services by trained TB survivors)



The Unite to ACT (Amplifying Community Action for TB Elimination) project was funded by The Global Fund to Fight AIDS, Tuberculosis and Malaria



Introduction

Under the Unite to ACT project, **trained TB survivors** provided **person-centered care** to people with TB and their families (as a peer support) at doorstep and at treatment facilities.

The project was implemented by **FIND** (principal recipient), **REACH** (sub-recipient) and two sub-sub recipients (**MAMTA; World Vision India**)



Project outline

Capacity building of TB Survivors



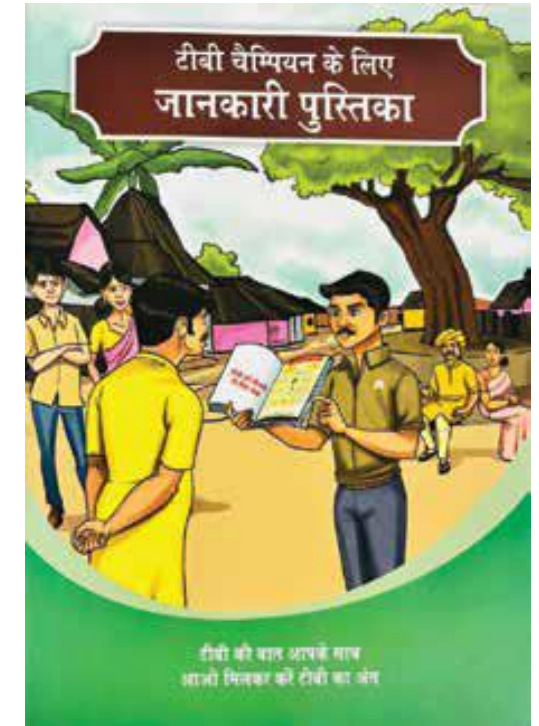
Identification of TB survivors,
in consultation with NTEP



Two-day Capacity building of TB
survivors (Modules on TB
disease, treatment, prevention)



Post training, consent was sought
from TB survivors to be enrolled as a
TB Champion (TBC) in the project.
Additional project specific trainings
were provided.



~1900 TB survivors trained

Implementation plan

Project was implemented in a **phased manner**:

Six months of mentorship
(involving doorstep delivery of
services)



Followed by **2-years** of facility-
based support.



TB Champion received a fixed honorarium for their time and efforts

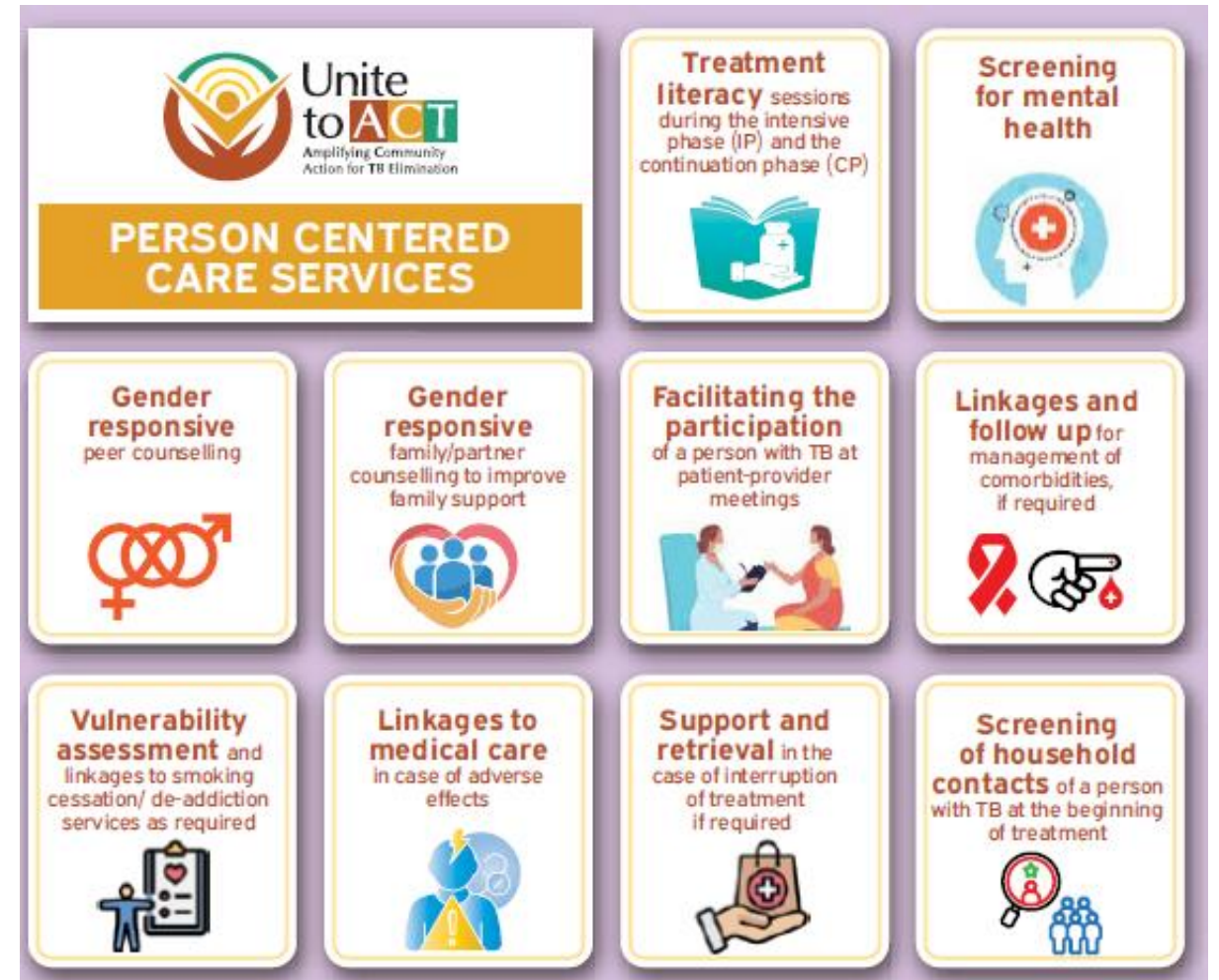


Community engagements
(awareness sessions, community leaders'
involvement)



Methods

- This is a **descriptive study** using **secondary data** from project involving people with TB who received person-centered care.
- **Ten services** were included in the package (Figure). Periodic follow up was carried out for TB patients, for treatment adherence and adverse event management.
- We share **three-year project** achievements including TB outcomes for those who received care under the project.

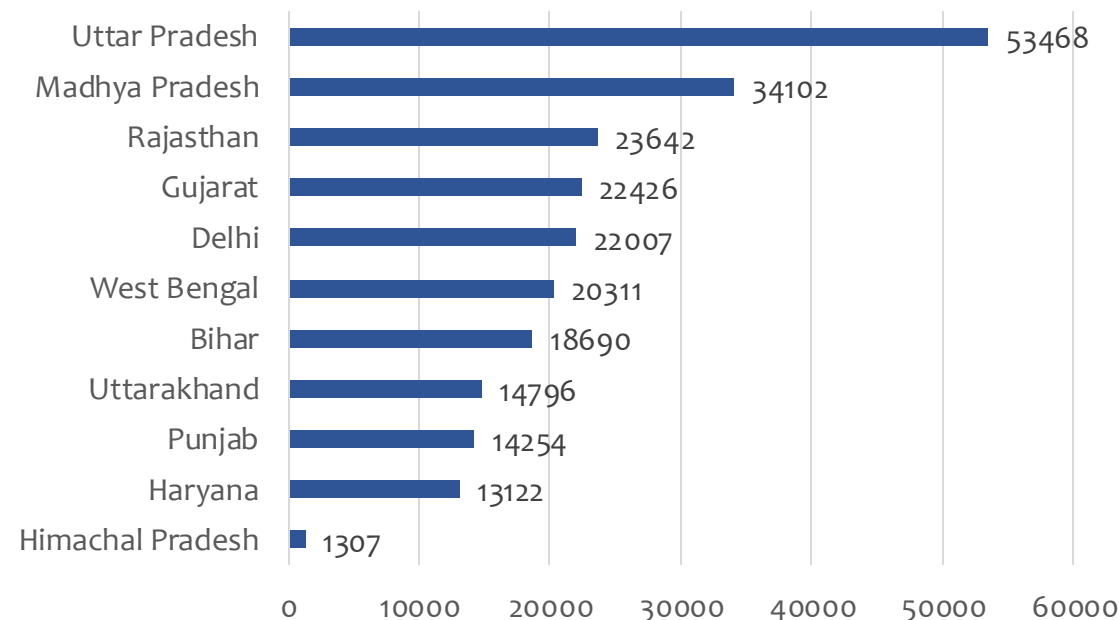


Results: People with TB characteristics

Under the project, trained TB survivors provided **person-centered care** to **238,125** people with TB and families during Jan22-Mar24 (including 90,117 people with TB who received support during the mentorship period and 1,48,008 under facility-based care) in 11 **‘direct-implementation’ states**.

People with TB who received care			
		N	Percent
Total		238,125	100%
Age (in years)	0-14	12,973	5%
	15 and above	225,152	95%
Gender	Female	98,071	41%
	Male	139,995	59%
	TG	59	<1%
Site of TB	Pulmonary	180,679	76%
	Extrapulmonary	57,446	24%

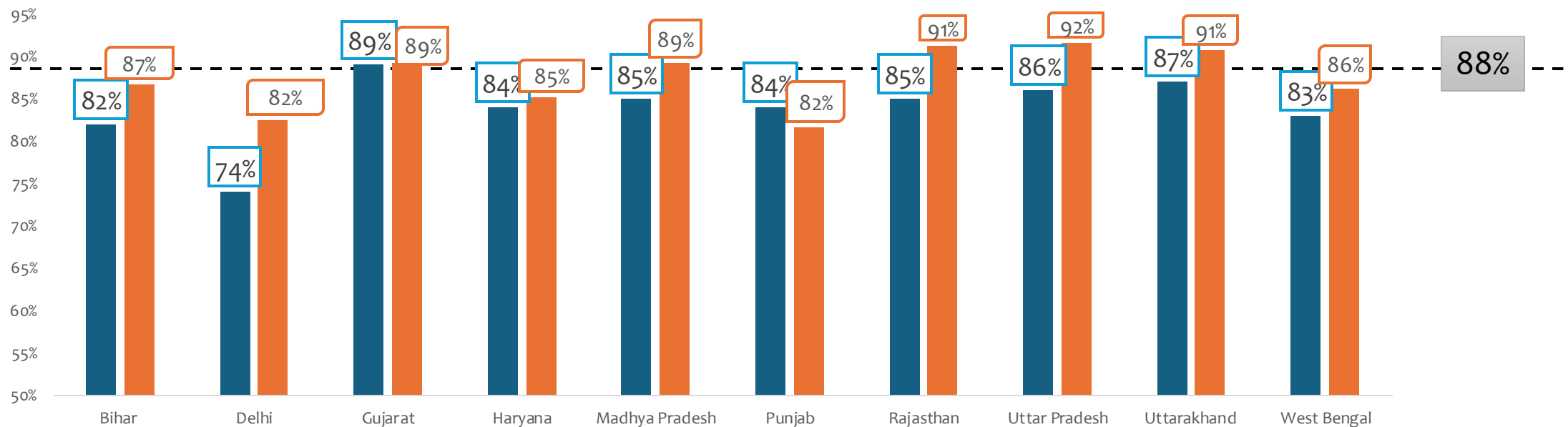
Geographical distributions of People with TB who received person-centered care



Results: Successful TB treatment outcomes

Of 1,34,445 people with TB that received person-centered care during Jan22-Mar23 and reported TB outcomes, 1,18,782 (88%) successfully completed the TB treatment*.

Proportion of successful TB treatment outcome improved in majority of the states during project duration compared to baseline (year 2021)**.



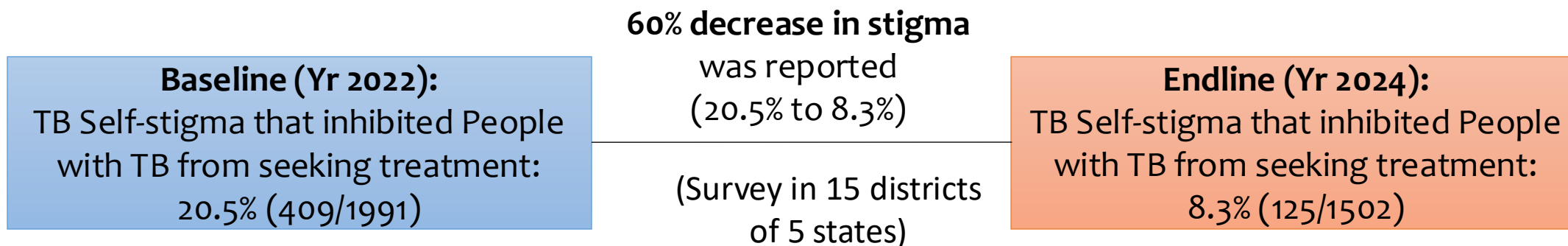
■ Successful TB treatment outcomes, among those initiated on TB treatment in 2021 (Baseline)*
■ Successful TB treatment outcomes, among those who received person centered care under project during Jan22-Mar23



*Treatment outcomes were recorded from Nikshay reports (NTEP records); ** For 2021 treatment outcome reporting of States, all the districts were included (Source: India Annual TB Report 2023)

Results: Efforts towards TB Self-stigma mitigation

- Trained TB survivors conducted **community meetings** focusing on minimizing TB stigma.
- ‘Mitigating the TB related stigma’ was one of the core-components in person centered care
- Individualized support was offered to people with TB and families (in cases of identified stigma incidences)



Other project activities

- ~400 community health officers were sensitized about activities of trained TB survivors, with support of NTEP, for continuation of TB survivors' efforts post project closure.
- Liaising with community leaders for Nutritional support/Rations and engaging them with '**Nikshay Mitra Initiative**'
- In 2021, the project received an additional grant through the **C-19 RM mechanism** of the Global Fund, for activities designed to support communities to respond to the COVID-19 pandemic.



Rapid response team

> 1,60,000 patients with TB received support.

Communications skilling

> More than 19,000 communication products were prepared by TBC.

TG TB survivor training

40 TG TB survivors were trained, of whom 28 were engaged; conducted ~650 meetings (> 3,500 participants)

Recommendations

- Continuous guidance and support of National TB programme (NTEP) and collaborative efforts of TB survivors, community leaders and key stakeholders
- Active participation of community representatives in preparation of context specific strategies including IEC materials.
- Regular training and hand-holding of TB survivors, to prepare a pool of trained TB champions for sustained project activities.
- Robust M&E mechanism (paper/app based, MIS) and frequent sharing of results with stakeholders.
- Discussion on challenges and mitigation plans at multiple levels (community, district, state, central) for providing improved care to people with TB.

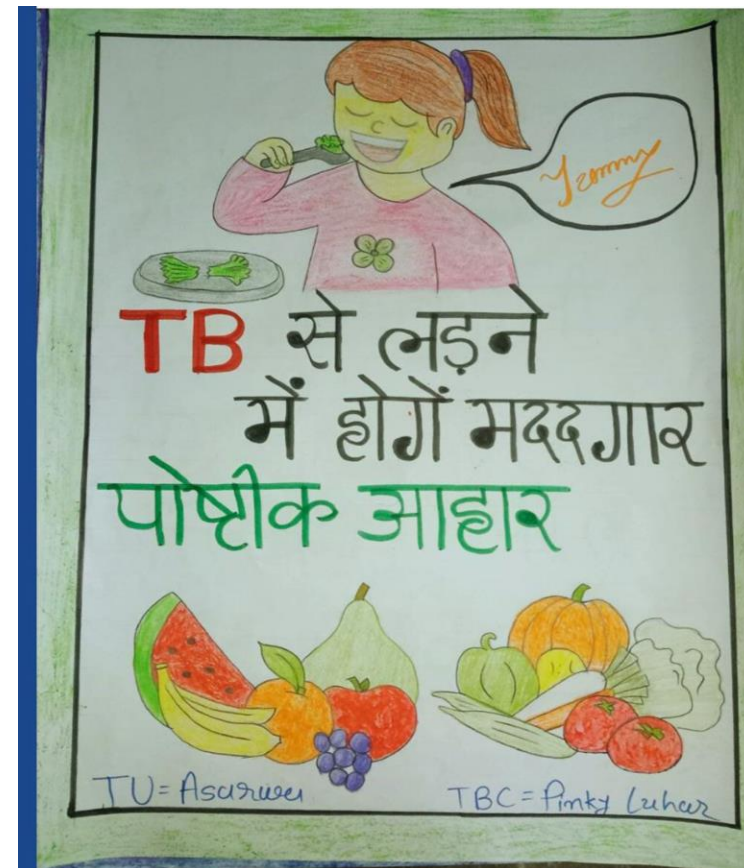
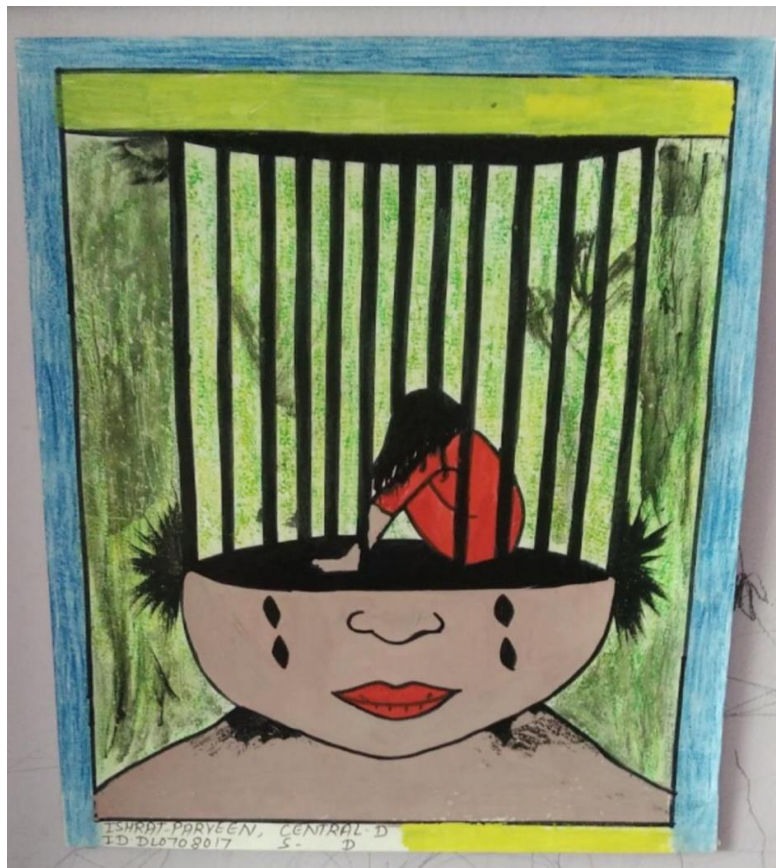


Conclusion



Trained TB survivors provided person-centered care to TB patients and families as an extended network of national TB programme in the community.

Scale up of community-based TB initiatives through NTEP resources, will help minimize TB stigma and overall TB burden.



We acknowledge the support of people with TB, their family members, TB survivors, project teams of Unite to ACT, NTEP India and The Global Fund to Fight AIDS, Tuberculosis and Malaria