







# COLOURS **OF HOPE**

**Profiles of TB Champions from** the LGBTQIA++ Community

#### **MESSAGE FROM DDG-TB**





Dr. Rajendra P. Joshi Deputy Director General Central TB Division



गजादी<sub>का</sub> अाज़ादीका अमृत महोत्सव 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 ddgtb-mohfw@gov.in 011-21400941

Message

I am delighted and honoured to note the impactful collection of stories of TB Champions from LGBTQIA++ community developed through the Unite to ACT Project. This publication showcases the extraordinary efforts of TB Champions from the LGBTQIA++ community in our fight against tuberculosis, as well as their tremendous resilience and courage. Each of the 10 Champions profiled in this publication have not only personally defeated TB, but drawn on their personal experiences to motivate, educate and support others in their community.

The impact of TB is often disproportionately borne by marginalised communities. The LGBTQIA++ community faces several barriers and challenges in accessing health care services, including stigma and discrimination, which can delay TB diagnosis, and adversely impact outcomes. These barriers are further compounded by gender-related disparities, which can affect how individuals experience and respond to TB.

India's National TB Elimination Programme is one of the first countries globally to develop and adopt a National Framework for a Gender-responsive approach to TB. We are committed to providing care that is truly gender-responsive. Similarly, we have also institutionalised the engagement of TB survivors as Champions. We have seen over the years the important role TB Champions can play, particularly as powerful peer supporters and in educating their communities about TB. As we work towards a TB-free India, the active involvement of and insights from LGBTQIA Champions will be invaluable in shaping our policies and programmes to become more effective and empathetic.

I congratulate the Unite to ACT Project for this pioneering initiative, and express my gratitude to every TB Champion, including those featured here as well their peers and colleagues, for their commitment and contribution as change-makers in our collective mission to end TB in India. Together, we can build a TB response that is truly inclusive, equitable and gender-responsive.

With deep appreciation,

(Dr. Rajendra P Joshi)

#### **MESSAGE FROM DR SANJAY KUMAR MATTOO, ADDG CTD**



Dr. Sanjay Kumar MD (Public Health): DTCD Adl Deputy Director General (ADDG) NTEP, Central TB Division



आज़ादी का अमृत महोत्सव भारत सरकार Government of India स्वास्थ्य और परिवार कल्याण मंत्रालय Ministry of Health & Family Welfare स्वास्थ्य सेवा महानिदेशालय Dte. General of Health Services निर्माण भवन, नई दिल्ली - 110011 Nirman Bhawan, New Delhi - 110011



I am honoured to present this distinguished anthology of stories commemorating the extraordinary endeavours of LGBTQIA++ TB Champions. These individuals have exhibited exceptional resilience and dedication in the battle against tuberculosis, proving that with determination and support, even the most formidable public health challenges can be surmounted.

LGBTQIA++ persons encounter unique barriers to healthcare, frequently exacerbated by stigma and discrimination. Despite these challenges, the TB Champions highlighted in this collection have emerged as leaders and advocates, transforming their personal experiences into powerful agents of change.

Over these nine months in the mentorship program, these champions have embarked on a series of transformative initiatives. They have taken the lead in organising community awareness sessions, equipping their peers with crucial insights into TB prevention, symptoms, and treatment. Their unwavering commitment to end stigma has been instrumental in dismantling barriers and fostering a more inclusive environment for those affected by TB.

Furthermore, these champions have not just engaged but truly made a significant impact through their meaningful advocacy with healthcare providers, policymakers, and community leaders. They have reaffirmed a gender-responsive approach to TB and ensured that the needs of LGBTQIA++ persons are integrated into national health programmes. Their peer counselling efforts have provided invaluable support to individuals navigating the challenges of a TB diagnosis, fostering a sense of solidarity and hope.

The stories in this booklet demonstrate the transformative power of diversity and illustrate how, despite the barriers, personal experiences can be transformed into catalysts for change, encouraging others to take up the mantle and join the fight against TB.

These stories in this booklet are powerful testaments to the urgent need for inclusivity and the pivotal role of community-led initiatives in advancing public health. They remind us that addressing the unique challenges faced by diverse groups is not just important but essential for achieving our goal of ending TB. This booklet will further motivate and galvanise LGBTQIA+ persons to serve as exemplary champions to fight the dual stigma of TB and diverse gender and sexual identities.

I extend my heartfelt appreciation to each of the TB Champions for their unwavering dedication and to all those who have supported them on this journey. May these stories inspire us to strive towards a more inclusive, equitable, and compassionate healthcare system.

टीबी हारेगा, देश जीतेगा / TB Harega, Desh Jeetega

#### **MESSAGE FROM DR. NISHANT KUMAR, JOINT DIRECTOR**





Dr. Nishant Kumar Joint Director Central TB Division





भारत सरकार स्वाख्य और परिवार कल्याण विभाग स्वाख्य और परिवार कल्याण मंत्रालय Government of India Department of Health and Family Welfare Ministry of Health and Family Welfare

#### Message from Joint Director, Public Health- Tuberculosis, Central TB Division

With great pride and joy, we introduce this remarkable collection of stories that honour the unwavering dedication and resilience of LGBTQIA++ TB Champions in our relentless fight against tuberculosis.

I congratulate REACH for demonstrating and engaging TB Survivors from the LGBTQIA++ community as TB Champions under the Unite To ACT project, supported by The Global Fund through FIND as the Principal Recipient.

This booklet serves as a compelling testament to the strength of the community, the vital importance of inclusivity, and the transformative impact of advocacy.

Through nine months of the mentorship programme, these champions have become vital advocates and educators within their communities. They have conducted impactful community awareness sessions, spreading essential knowledge about TB prevention, symptoms, and treatment options. Their efforts in leading anti-stigma campaigns have been crucial in reshaping perceptions and fostering a more supportive environment for those affected by TB.

Moreover, these champions have engaged in robust advocacy with various stakeholders, ensuring that the voices and needs of the LGBTQIA++ community are represented in TB policies and programs. Their peer counseling initiatives have provided critical emotional support and guidance to fellow LGBTQIA++ individuals diagnosed with TB, building a network of solidarity and hope.

These stories vividly demonstrate the remarkable achievements possible when we prioritize diversity and inclusivity. They showease the crucial impact of community-driven efforts in advancing public health and highlight the need to address the unique challenges faced by different segments of our population.

As we read and reflect on these narratives, let us be inspired by the courage and dedication of our LGBTQIA++ TB Champions. Their work is not only changing lives but also setting a powerful example for how we can create a more inclusive and equitable healthcare system for all.

(Dr. Nishant Kumar)

टीबी हारेगा, देश जीतेगा / TB Harega, Desh Jeetega

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#### **MESSAGE FROM FIND**

Tuberculosis (TB) continues to remain a significant public health challenge in India, affecting a staggering 2.8 million people annually. Although treatable, fighting TB requires access to quality diagnosis, uninterrupted medication, nutrition, and mental fortitude to deal with the debilitating side effects of treatment, all of which take a toll on the resources and capacities of those affected by TB. In the last few years, India has made remarkable strides against TB, and the National TB Elimination Programme (NTEP) has had numerous successes in TB control by introducing and scaling up new diagnostic tools and effective treatment regimens.

The success of any public health intervention is rooted in the community where it is being implemented. Communities can play a critical role in the success of any healthcare intervention by helping to address socio-cultural barriers, providing feedback on the efficacy of interventions and encouraging their uptake. The voices of those affected by TB are unique and must be given centre stage. Recognizing this, the National Strategic Plan for TB Elimination (2017-25) calls for a community-based and person-centered approach to TB, as a key strategy to reach the unreached and to support people with TB.

The Unite to Act project implemented by REACH in partnership with FIND and supported by The Global Fund from 2021-2024 worked to build the capacity of TB-affected communities, promote rights-based, gender-responsive and equitable services for all and accelerate the uptake of community-led activities in 10 states of India. Further, it supported 15 additional states to mainstream community engagement into NTEP policies, and strategies, to strengthen the functioning of national, state and district TB forums; and ensuring effective engagement of communities.

The project succeeded in establishing a cohort of TB Champions across the project states, who served as invaluable links between the programme and the community at large. These TB champions supported persons with TB, and helped identify people with symptoms of TB and linked them with care. The courage demonstrated by these TB champions in sharing their stories also helped address the persistent stigma associated with TB and encouraged people to come forward to be tested and treated.

This report clearly highlights the criticality of involving communities affected by TB for a successful TB response. The inspirational stories of the TB champions mentioned in the report, clearly demonstrate how empowered communities can play a significant role in accelerating the end of diseases like TB that have plagued humankind for millennia.

We are proud to have been associated with the Unite to ACT project. A big congratulations to the REACH and FIND teams for their commitment to the implementation of Unite to ACT. Finally, to all the TB Champions, thank you for your efforts and commitment to help and empower those affected by TB.

TB Harega, Desh Jeetega.

Dr. Sanjay Sarin Vice President, Access FIND

#### **MESSAGE FROM DIRECTOR, REACH**



Resource Group for Education and Advocacy for Community Health

#### Director's Message

I am delighted to share with you a heartfelt collection that embodies the resilience and transformative power of TB Champions from the LGBTQIA+ community. In our publication, "Colours of Hope," we shine a spotlight on remarkable journeys that intertwine personal struggle with profound advocacy.

TB remains a major public health challenge in India, exacerbated by societal stigma and inequalities that disproportionately affect marginalised communities, including LGBTQIA+ individuals. Stigma, both towards their identity and the disease, creates a double bind that discourages them from seeking help. Therefore, it helps to have a TB Champion from their community offer the care and support they need to overcome stigma and the disease.

At the heart of this collection lies a celebration of courage — the courage to defy stereotypes, to demand dignity, and to advocate for change. Our Champions have not only fought TB but have also become volces for justice and equality, reshaping the discourse around health and human rights. Their experiences underscore the importance of intersectionality in our fight against TB and the need to address the unique vulnerabilities faced by LGBTQIA+ individuals by building a healthcare system that serves everyone, equally and without judgment.

Our goal in sharing these stories is twofold. First, we aim to celebrate the incredible achievements and contributions of TB champions from the LGBTQIA+ communities. Second, we hope to inspire others by showcasing the importance of compassion, community support, and the need for inclusive policies.

The fight against TB is far from over, but with champions like these leading the charge, the future burns bright. We, at REACH, are humbled to walk alongside them, amplifying their volces and advocating for a world where every individual, regardless of sexual orientation or gender identity, can breathe freely.

Brujo Ananthakishan

Dr Ramya Ananthakrishnan Director, REACH

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### Engaging TB Survivors and Champions from the LGBTQIA++ community in India's TB response

India's TB programme is deeply committed to the engagement of TB-affected communities, including those who are the most vulnerable and marginalised. The voices of LGBTQIA++ communities – and particularly those who have survived TB themselves - has for long remained unheard. In 2022, through the Unite To ACT project, supported by The Global Fund to Fight AIDS, TB and Malaria, FIND as a principal recipient and REACH as sub recipient organised two capacity-building workshops for TB survivors who identified as primarily transgender. These first-of-their-kind workshops resulted in 44 TB Champions from the LGBTQIA++ community, from across 6 states of India.

28 TB Champions joined the flagship TB Champion Mentorship Programmme, with the mandate to share what they'd learnt with their communities. Over a nine-month period, these TB Champions conducted community awareness meetings, led anti-stigma campaigns, advocated with local stakeholders, and provided peer counseling support. This multifaceted approach reflected a commitment to addressing the complex challenges faced by the LGBTQIA++ community in accessing TB care and support.

The community awareness sessions led by champions served as vital platforms for disseminating crucial information about TB prevention, symptoms, and treatment options, empowering their peers with knowledge and action. Their relentless efforts in anti-stigma campaigns challenged stereotypes and nurtured an environment of acceptance and support for those affected by TB within their communities.

Moreover, TB champions actively engaged with stakeholders, advocating for policies and programmes that prioritised the needs and rights of the LGBTQIA++ community in TB care. Through peer counseling support, they offered invaluable emotional guidance and solidarity to individuals navigating the complexities of TB diagnosis and treatment, embodying the spirit of empathy and compassion.

The profiles of TB Champions featured in this publication not only celebrate their courage and resilience, but also present a vision for a future where healthcare is truly equitable and inclusive for all.

### KEY ACHIEVEMENTS OF THE MENTORSHIP PROGRAMME (MARCH 2023 TO MARCH 2024):



from the LGBTQIA++ community trained as TB Champions.

### **TB** Champions

28

engaged i<mark>n the</mark> Mentorship Programme.

### Over more than **800** community meetings organised by the TB Champions, for over

**7000** people in the community,

### **434** Advocacy meetings

with different stakeholders,

### 12 LGBTQIA++ people with TB-provided person-centered

care services, and

### **32** Anti Stigma Campaigns

conducted by these TB Champions.

# POWERFUL STORIES FROM LGBTQIA++ TB CHAMPIONS

# MANOHAR



When a nomadic Baba (ascetic) in his district was diagnosed with TB, and was also found to be HIV positive, Manohar had a difficult time convincing him to get treatment. "He refused to accept that he had HIV," the 40-year-old TB Champion says. "I had to talk to him at length, take him aside, and promise confidentiality... That's when he told me he had engaged in sexual activity in the past, and finally agreed to get treatment."

Manohar, who has been a health worker for the last 15 years, informed the managers of the temple where the Baba was staying that the ascetic had contracted TB – he did not reveal his HIV status to anyone – and with their help, got him the treatment he needed. "He was recovering well, but a few months later, he moved to another city and died there," Manohar recalls.

What happened to the Baba - and other similar stories - weigh on Manohar's mind as he creates awareness about TB and HIV across Uttarakhand, specifically in the district of Uddham Singh Nagar. But the challenges and the uncertainty that come with the work are nothing compared to the joy he feels when he's able to get across to people and make them understand the illnesses, help them get over stigma, and accept their family members who are queer, have TB, or are HIV positive.

A queer person who has survived TB, Manohar is married to a woman and has two children. His family, including his wife and mother, accept his queer identity – they know that he performs as a woman in Ramleela functions, that he works with trans and queer persons, that he is a TB Champion who spreads awareness to hundreds of people every day. "When I got TB in 2010, my mother was very scared," Manohar says. "But I was aware of the symptoms, I got myself tested and took the medication on time, and recovered in 6 months."

Manohar has been working on TB awareness for the last four years, and when he was asked to sign up as a TB Champion with REACH, he readily accepted. During the nine-month period, Manohar helped a lot of LGBTQIA++ persons, especially transgender women, get tested for TB, and helped those who were diagnosed with TB to get their medication and their government benefits on time. He conducted advocacy meetings with doctors in government hospitals, as well as field meetings with transgender persons.

While he has been working in the health sector for a long time, the nine-month stint as a TB Champion with REACH was special. "Sometimes in this work, we don't get money on time, we're not given our allowance properly. But with REACH, I was paid on time, and I was treated with respect. They understand the community, and that makes a big difference," he says.

Manohar travels a lot for his work, and never misses an opportunity to talk to people about TB, HIV, and LGBTQIA++ issues. He visits colleges and talks to students about TB, HIV, polio, cancer, and creates awareness about helplines like Childline too. "Recently, I met the inspector of our area, and I convinced them to call me the next time they have a meeting with all police officials. I asked them to give me 15 minutes so that I can explain to the force about TB and HIV, and why they shouldn't discriminate against transgender and male sex workers," he says.

With gay and bisexual men, transgender women, and sex workers from various communities, Manohar has to work harder to provide support. "They get scared," he explains, because of the discrimination that LGBTQIA++ persons and sex workers face in the health system. With his access to officials and health system workers everywhere, built through the last 15 years, Manohar goes along with them to get them tested and get medical help. "It's important for people who are at high risk to get tested every 6 months," he stresses.



# JAHNAVI



"A sex worker can ask a client to use protection for HIV, but she can't ask them to use protection for TB," says Jahnavi, a 48year-old transgender woman and TB Champion from Chattisgarh's Bilaspur, who has been doing social work since 2007. "A lot more work is needed on TB," she says.

Jahnavi is HIV positive and a TB survivor who has worked on HIV prevention and LGBTQIA++ rights, and now runs her own community based organisation called Samman Sankalp Samiti. Hailing from a large family. Jahnavi had to drop out of school when she was in Class 7 because her father found it difficult to educate her and her 9 siblings. She worked several odd jobs including as a cleaner in a hotel to earn money. Hosted in Delhi by one of her older sisters, Jahnavi worked at a factory while completing a beautician course - and returned home on finishing the course to set up a beauty parlour. She earned enough money to get her sisters married – and then her family wanted her to get married as well. She was not out with her transgender identity to the family.

"I got married, and my wife and I have two children," Jahnavi says. "She's a great inspiration for me," Jahnavi says of her wife Rinki Arora, who also works in the HIV awareness space. Jahnavi came out to her wife during the course of their marriage, and while they no longer have a sexual relationship, the couple continues to live together and have a strong bond.

Jahnavi was diagnosed with TB in 2014 – and at the same time, she realised she was HIV positive. "I was scared to tell my family about it," she recalls, "In fact, I told them that I had cancer. Kinnar (transgender) persons face a lot of stigma if anyone comes to know that they have TB or HIV. My LGBTQIA++ community now knows about my HIV status, and their support has been incredible. It's important for other members to see that they are not alone," she notes.

Her recovery was long and difficult – it took her a year and a half to find her feet. "This is literally my second life," Jahnavi says.

And in this second life, Jahnavi is determined to transform her struggles into strength. Jahnavi joined a targeted intervention program as an outreach worker, focusing on HIV prevention among transgender persons. Her dedication and passion quickly propelled her to roles as a counsellor and then program manager. Eventually, she founded her own organisation – Samman Sankalp Samiti, based in Bilaspur. Funded by NACO, her project focuses on HIV prevention. Society needs to understand TB and HIV better, Jahnavi says, and survivors need to be aware of all the schemes available to them. As a TB Champion, Jahnavi worked closely with two other survivors to create awareness among trans persons in Chhattisgarh. Reaching out to the community has not been easy, Jahnavi explains. "Initially, accessing the community as an outsider (who was not part of traditional trans communes) was difficult. I've now become a chela (follower) of my guru, Nagina Nayak, and it's become much easier to reach out to a large number of trans women to raise awareness now," she says.

Jahnavi recalls her training with REACH in Delhi as an important intervention, especially the sessions by Simran Sethi, a trans community leader in Delhi. "I really enjoyed the sessions and I learned a lot," Jahnavi says, "and it was great that we were taught more about TB by other transgender persons. The training was an opportunity to meet other trans TB survivors and it was really eyeopening."

In her nine-month stint, Jahnavi has reached out to trans persons from different walks of life. "Many trans women are engaged in traditional occupations like Badhai (performing at celebrations), and because of their work hours, it was difficult to reach out to them. But slowly, I have managed to talk to them about the importance of TB prevention and testing. I've also reached out to trans women who beg on trains, as they are at high risk of contracting TB," she says. In the course of her social work, Jahnavi has also managed to finish Class 12 – a proud achievement, she says. "I want to continue my work of creating awareness because the work on TB cannot stop," Jahnavi says.



# VERONICA



"I lost out on studying at an IIT by 7 marks," says Veronica, an MBA graduate, a resident of Delhi and a TB Champion. The 25-year-old was an intermediate student in 2015 when she was diagnosed with TB, and had a long and difficult recovery spanning nine months. Just a few months later, she had to give the IIT-JEE entrance exam. "I've always been a smart student, and I managed to study the whole year's course in a matter of three months. But I couldn't crack the IIT-JEE exam by just 7 marks," Veronica rues.

Veronica's life has seen a series of struggles and she has worked past all of them with courage. She hails from a conservative family in West Bengal, and her mother died when she was a toddler. By the time she was 13 years old and realised she wasn't the "boy" that everyone saw her as, she could not continue living with her father and step-mother. "I ran away," she says, "and came to Kanpur. I started living with the Kinnar community, and I started working to earn a living." She continued her education despite these trying circumstances, and when a coaching centre realised her potential, they enrolled her in their JEE course for free. In 2015 – still a minor – she suddenly lost a lot of weight. "I was coughing a lot, I wasn't feeling very good. I went to a doctor, but because I had no money, they refused to treat me," Veronica says, "I didn't even know that there are government hospitals where I could get treatment for free."

For several weeks, Veronica was bedridden. A friend who came to know of her situation helped her – she was diagnosed with TB and got her treatment from a hospital in Kanpur. Her friend provided her with food and helped her with medication, and it took her 9 months to a year to completely recover.

By 2019, Veronica finished her BBA with a scholarship, and by 2021, she finished her MBA, both from private colleges. "I wanted to achieve something," she says. The Hijra community supported her with her education, but she still needed a lot more money to complete it. She turned to sex work, like many other transgender women, and finished her education using the money she earned.

When she got the opportunity to become a TB Champion with REACH in 2023, Veronica was very happy. She attended a training session conducted by REACH in Delhi, where many of the trainers were trans persons. "This was the first time I've ever been to a big hotel," Veronica says, "There were so many trans, lesbian, gay persons in the training, and it felt very good to be in that space. I learned a lot from the trainers about the different types of TB, and I was very proud that I was able to answer their questions correctly when they quizzed us. The booklets that were given to us were also very useful. And in the evenings, the participants spent time together. It was fun."

In the 9 months that she worked as a TB Champion post the training, Veronica has reached out to at least 400-500 people, many of them one-on-one. She talked to them about the fact that TB is completely curable, that they should take their medication on time and eat nutritious food to get better sooner.

Veronica mainly worked with trans communities in Delhi, and faced a lot of resistance when she tried to create awareness. People who live in the Dera (trans communes) refused to entertain any talk of TB for two reasons – because of the stigma around TB, and because they believed this wasn't worth their time. Many of them are engaged in sex work, and saw the time spent at TB awareness meetings as time lost from work.

Veronica had to use several strategies to reach the trans women in Deras, get them to attend awareness sessions, and help them get the help they needed. "I could never go in directly and start talking about TB. I had to start with other things and then get to the point I was trying to make. As for the Nikshay baithaks (TB awareness meetings), I would always involve men in the meetings as well so that the sex workers thought there was a possibility of getting a client," Veronica says. And when someone was scared of being stigmatised in the community if their TB status was revealed. Veronica made sure she acted as a medium between healthcare providers and the community. "There are several instances where I've had to connect the women with doctors on the phone, where neither of them knows the other's identity. It was only because of this confidentiality that many trans women got the treatment they needed."

Veronica signed up to become a TB Champion because she believed this was a good work opportunity, and a chance to help other trans people. "I don't want the others in the community to go through what I did – I want them to get the help they need on time," Veronica says, "and I continue to volunteer when people need help with diagnosis or treatment. Everyone in my community knows I know all about TB, so they reach out to me whenever they need help."



# AKRITI



"I am a TB Champion because my transgender sisters should not go through what I had to," says Akriti, a resident of Delhi who has been working on HIV and TB awareness for several years now. Akriti was a minor when she survived TB, and has faced a lot of discrimination as a transgender woman, especially early in her transition. As a TB Champion, not only does she ensure that she's educating trans communities in Delhi about the infection, she also ensures she's educating the health system about trans identities.

Akriti comes from a middle class family that runs a grocery shop, and has finished her graduation. She started her career with an NGO doing targeted intervention on HIV, and when she got the opportunity to become a TB Champion through REACH, she was happy to take it up. "There were a lot of things I faced when I was undergoing treatment for TB, and I want to change that," Akriti says, "starting with how we as transgender persons are addressed in hospitals." "When we start transitioning, trans women face a lot of discrimination because of the way we look. People don't understand what they're seeing, and therefore treat us poorly. At hospitals, they use our documented name only – and many trans persons don't have ID cards with our chosen name and gender, especially in the beginning of our transition journey," Akriti explains.

"I would be sitting in the waiting room, dressed as a woman, and suddenly they'll call out my deadname – a man's name. Others in the waiting room used to look at me very weirdly," Akriti says. But the bigger issue was doctors themselves asking insensitive questions about her identity.

So when she started working as a TB Champion, one of the most important things she did was to meet the health system workers and create awareness about trans identities. Akriti explained LGBTQIA++ issues to doctors, nurses, and other hospital workers. And simultaneously, she met trans communities and created awareness about TB.

Outreach in Deras (trans communes) is not easy, Akriti says. There is a hierarchy in the system, and outsiders can't simply walk in and start talking about TB – or anything else. "I had to make friends with the women," Akriti says, "I would ask them how they were, how their day was, what their work is like. When I start talking to them, they start talking to me, and ask me about my work. That's when I would bring up that I'm a TB Champion – segueing into TB awareness." Akriti believes her work as a TB Champion with REACH was extremely important, because trans communities often don't get the benefits of government schemes soon enough. "There are benefits like monthly provision for nutritious food, loans etc that people on treatment for TB and transgender persons can get. As a TB Champion, I take this information to my trans sisters, and help them access what is their right," Akriti says. The NALSA vs Union of India judgement by the Supreme Court in 2014 promised several rights to transgender persons including housing, employment, education, and health. "But we're still fighting for these basic rights, even today," Akriti says, "The community is not educated enough, and we don't have enough money. I believe it's important that as the next step, either the government or REACH does awareness sessions at all hospitals and dispensaries about trans communities and identities, like I did as a TB Champion."



## ALFIYA



"I help TB survivors access government schemes and ensure they get the support they need," says Alfiya, a TB Champion from Mumbai. "I ensure that trans women from high risk communities get tested for TB every 3 months. Today, we've reached a stage where the women I've reached out to know that they should get themselves tested even if they have a cough for two days."

Alfiya is a transgender woman dedicated to aiding TB survivors in her community, ensuring they navigate the healthcare system and access government schemes effectively. Her own battle with TB and the discrimination she faced has fueled her passion to support others in similar situations. In 2006, Alfiya contracted non-pulmonary TB. The TB diagnosis brought a wave of challenges, both from the disease and the social stigma attached to it. "I underwent treatment for six months at a private hospital, and a surgery was performed to remove nodules. After this, I felt relieved, though medication continued," she recalls.

When Alfiya got the opportunity to become a TB Champion, she took it up because it meant helping other trans women like herself. The

training by REACH in Delhi not only helped her understand TB deeply, it also enabled her to help others access various government schemes available to people with TB and survivors, and she regularly ensures that trans women are able to access these benefits. "I help people with TB within the community and outside at every stage of the diagnosis and treatment for this disease, using the things I learned during the training" she says.

Alfiya highlights the unique risks faced by the transgender community, particularly those involved in sex work. "Our community is at high risk because it's hard to know if a customer has TB. This makes sex workers more vulnerable," she says. In her outreach work, Alfiya insists on the need to wear masks in crowded spaces, and to get tested every three months. "I advise them not to remain hungry as this worsens the condition of a person with TB." This proactive approach has significantly improved early diagnosis and treatment, she says.

Having faced discrimination herself, Alfiya notes a positive shift in societal attitudes towards transgender persons. "Due to the efforts of our community, transgender people now face less discrimination. We (TB Champions) take people to the hospital and assist them at every stage during the treatment period. Doctors and paramedical staff go out of their way to help and prioritise our patients," she remarks.

However, one of the challenges she faces in her work is the window of time for testing in government hospitals, which does not suit transgender women engaged in traditional work. "Testing is available only till 9.30 or 10 am – and this is usually the time when many in the community are working. They will have to miss out on their livelihood to make it in time for the testing – extending the hours will definitely help," she explains.

## NAVNEET



"Many trans women don't take their health seriously until they reach a point where they can't even move," says Navneet Sharma, a TB Champion from Delhi who has been working extensively with trans communities in the capital to raise awareness about TB. "You can't blame them. They have to focus on their livelihood. But it's important to take care of their health, and I stressed on this during my work as a TB Champion," she says.

Navneet is an arts graduate who once dreamed of becoming a Biomedical Engineer. She dropped out of her Biomedical Engineering course when she started transitioning because of severe transphobia, which has continued across different jobs that she's tried to hold, including at a call centre. She started working in HIV awareness, first as a field worker, then a counsellor, and is now a programme manager with an NGO focussing on HIV prevention.

When she got the opportunity to sign up as a TB Champion, she agreed because she

believes that people with TB face the same stigma in society as those living with HIV. The stigma worsens when one belongs to an LGBTQIA++ community, she explains. Navneet got TB when she was a teenager and living with her parents. "This was around 2008. I was very young, and I didn't face any stigma or discrimination," Navneet says, "I finished my treatment in 6 months at a government hospital, and did not face any issue with it." But her work with trans communities as an adult has revealed the stigma that TB can cause. Many trans women who are forced to take up sex work and begging to make a living are afraid on two counts – firstly, whether they will be treated with respect by the health system; and secondly, whether they will face stigma in society if their diagnosis is revealed.

As a TB Champion, Navneet has focussed on early detection, treatment adherence, and prevention strategies for TB. She's reached out to hundreds of transgender women on a one-on-one basis to create awareness about the issue, and connected them to health facilities if they're diagnosed with TB. She talks about her own experience as a TB survivor to encourage others to seek help.

"Trans women are treated badly in hospitals, especially if they're not educated," Navneet says, "and since most trans people don't have family support, they don't get good care when they contract TB. Which is why she accompanies them if they need to go to hospitals. "Hospital staff tend to discriminate against trans women – some people in hospitals assume that every trans woman is a sex worker and start approaching them for sex." Navneet believes it's important to have sustained training and outreach for hospital staff – starting from the security guard to the doctors – on LGBTQIA++ issues and identities. "They still use our deadname when calling out patients – this has to change," she stresses.

The training experience with REACH and her 9-month stint as a TB Champion has strengthened Navneet's resolve to become a leader in the community. "The training was done by trans persons and that was a good experience overall. I want to become a leader in the community because, in future, I don't want trans women to face the kind of discrimination we do today."





# MUSKAN



"My mother had TB when she was pregnant with me, and so I knew about the virus. When I got the symptoms in 2019 therefore, I knew I could have TB," says Muskan, a TB Champion from Madhya Pradesh's Indore. Recovery took six months, and although her sister was supportive, Muskan decided to stay elsewhere during this period because she was afraid her sister's children might get affected.

Today, Muskan reaches out to hundreds of transgender women like herself to encourage them to get tested, create awareness about symptoms, and help them complete their course of medication if they are diagnosed with TB. The 45-year-old health worker has been in the sector since 2008, creating awareness about HIV among trans communities. Many transgender women are forced to take up sex work for their livelihood, increasing their risk for both HIV and TB. Muskan, who is also living with HIV, travels long distances when needed to ensure she champions TB prevention in the community. The reason, she says, is to ensure that no one else suffers. When she was diagnosed with TB, a colleague helped Muskan with her recovery, and later, he encouraged her to work as a TB Champion with REACH. Describing him as an elder brother, Muskan says, "He believed in my potential – he encouraged me by pointing out I would be able to make an even greater impact on those suffering a similar plight if I leveraged my experiences and knowledge."

Her experience coupled with the REACH TB Champion training in Delhi equipped her to reach out to a lot of people. "I now have the knowledge and skills to educate others about TB prevention, treatment, and the importance of completing the treatment regimen," she says.

Muskan couldn't finish her schooling when she was young; but that doesn't stop her from using the education she has to reach out to officials and build networks to help prevent TB and HIV. "I am popular in the city where I work, because I know Collectors, higher police officials and other officials very well. I let them know that I am educated and I can feed myself by working hard and they recognise my work as well."

She actively engages with community members, particularly those who live in Deras (trans communes) far from the city centre. By educating them about TB symptoms, dispelling misconceptions, and encouraging them to get tested, Muskan plays a crucial role in promoting early detection and treatment adherence. Her own experience as a TB survivor battling HIV served as a powerful testament to the effectiveness of treatment and the possibility of living a healthy life. She often tells them, "Even if others aren't in support of those affected, I assure all of you that I will always support you all, that you will also recover from TB like I did." she fosters a sense of understanding and acceptance within transgender communities as well as others. She ensures that she accompanies trans persons to the hospital to allay the fear of discrimination.

Muskan's work extends beyond simply raising awareness – she actively challenges the stigma often associated with TB. By openly discussing her own diagnosis and recovery,







"Even when we're cured of TB, survivors face discrimination," says 31-year-old Annu, a resident of Delhi and a TB Champion who has been creating awareness among transgender persons in the city about the illness. "There is always the fear that people will discriminate if they find out. This is why awareness is crucial," she says, explaining why she chose to become a TB Champion.

Annu contracted TB around 10 years ago, and her recovery took almost a year. She stayed in a separate room in her home, and was given separate vessels because of the fear that the infection may spread to others. As a transgender woman, this isolation hit her harder. Annu realised her trans identity when she was a student in Class 7; ever since, navigating society as herself has been difficult. "Even when your family is ready to accept you, society doesn't. They keep needling family members about our identity, and in turn the family takes this frustration out on us," Annu says. While her mother and sister treated her well, the fact that she couldn't work for a year meant she was dependent on the family monetarily.

Her TB treatment was also made difficult because of the discrimination that trans persons face. "We face uncomfortable stares and rude behaviour in hospitals," Annu explains, "they avoid us in favour of other patients. When there is a shortage of medication at dispensaries, trans persons are the last in line. This needs to change," she says.

So when she received the call to sign up as a TB Champion, she enthusiastically said yes. Despite having a BA degree, Annu does traditional work including Doli-Badhai with other transgender women for a living, because job opportunities are difficult to come by. She lives with her community in a Dera, and this opportunity with REACH allowed her a chance to create an impact as well as earn a livelihood.

Following the training by REACH in Delhi, Annu has been holding meetings frequently to create awareness about TB, not just among transgender communities, but also lawyers, professors and other professionals. "I made it a point to alternate my Nikshay Baithaks between the trans community and others outside the community," she explains.

The first two months of outreach was difficult for Annu. Building a rapport with the communities she was working with took time, and she had to explain a lot about TB, and the side effects of medication to people living with



HIV. She discussed nutrition deeply with the people she reached out to, because in her experience, TB medicines only work if one is well nourished and motivated to get well.

"I told people that anyone can get TB – that this is not something to discriminate against a person for. I told them that it was completely curable. I gave them my own example, I could not have motivated them otherwise," she says. And compared to the treatment she received in hospitals when she had TB, Annu believes things are slowly changing for trans people. "There is more awareness about trans persons in the health sector today, compared to 8 or 10 years ago," Annu says. "Programs such as these, where we are sensitising people about TB as well as trans identities, should continue to be done in a sustained manner for us to see long term change. Some behaviours are changing – and keeping at it will ensure the discrimination reduces significantly."



# GANESH



"India wants to eradicate TB by 2025. But how will they do it if the public health system isn't equipped to provide TB medication properly?" asks 53-year-old Ganesh, a TB Champion from Mumbai who belongs to the LGBT community. "First of all, the counsellors who are appointed to interact with persons with TB should be survivors themselves – only then can they understand how to behave with others," Ganesh says.

Ganesh is a social worker who signed up to be a TB Champion when the opportunity came up with REACH, because they want persons with TB to be treated well by the health system. And this opportunity helped them learn a lot about TB, and gave them the power to change lives, they say. "Before this training, I did not know much about TB although I myself am a TB survivor," Ganesh says. "I had pulmonary TB in 2010, and so I knew about it. But with the REACH training I learned about extra pulmonary TB, MDR TB, and a lot more. And this knowledge enabled me to help people on the ground," they say. Most importantly, they learned to do advocacy for persons with TB, Ganesh says.

As a Champion, Ganesh has helped several persons with TB get the relief they're promised by the government - and in the process, realised there's a big problem for transgender persons with TB that the government must address. "Most trans persons don't have bank accounts." Ganesh says, "And the government therefore tells them to give the bank account details of a blood relative. They end up giving the details of an uncle or a cousin – and what I found was that even when the government has transferred the money, the relative doesn't end up giving it to the person with TB." Ganesh has personally taken photos of money transfer records in government offices, tracked down the relative in guestion, and in some cases, managed to get the transgender person with TB the money that's rightfully theirs.

"It's just Rs 500 per month – not a big amount. A person with TB spends around that much on a single visit to the hospital, and they have to visit the hospital at least thrice a month. On top of that, they also lose out on their livelihood on those days," Ganesh explains. "But at least if this small amount is given as cash, the trans women can have a glass of juice on these days," they say.

When Ganesh suddenly fell ill in 2010, they were first taken to a private hospital by the family, who admitted them for several days, took Rs 40,000, and discharged them without proper tests. Fifteen days after they were discharged, the symptoms returned. "I was coughing a lot and I didn't understand what was happening. My weight was around 70 kg, but after the symptoms started, I lost almost 35 kg in a short period of time. My family was



extremely poor, despite which they took me to a private hospital and paid a huge amount to get me treated. But I did not get well," Ganesh recalls.

It was then that they went to a government hospital in Mumbai and got a TB diagnosis. They completed their treatment for pulmonary TB for six months, and recovered fully. But the experience they had in the government health system left a sour taste in their mouth. "At the hospital, they would keep a table near the door, and lay out medicines there. They'd call us there one by one – we were strictly instructed to bring our own water from home – and then they'd make us swallow the pills while they watched. And then, they'd dismiss us. We were shouted at and treated as vectors of disease," Ganesh says.

And things haven't changed too much even today, Ganesh says. As a TB Champion, Ganesh worked a lot with transgender persons with TB, and during their visits to hospitals along with clients, they witnessed widespread discrimination towards anyone who is 'different'. "In Mumbai, migrants especially from UP or Bihar are treated poorly in the health system by workers who are native to Maharashtra. Transgender persons, LGBTQIA++ persons, visibly Muslim persons – everyone faces apathetic behaviour. As it is, persons with TB are treated badly." And this can only change if TB survivors are employed as counsellors and Champions, Ganesh insists. "A TB survivor knows what another person with TB is going through, and therefore will be more considerate. It's not enough that the person sitting in that position is educated – what use is the education if they don't know how to treat people well?" Ganesh asks.

Logistically, too, there are things that need to be improved, Ganesh explains. "There are times when a person with TB is given medication for just 15 days and asked to come back on the 16th day – this person is already weak, and has travelled once to the government hospital to get the medication. Most times, they can't make it on the 16th day, or the 17th or 18th day. They come 20 or 25 days later, and they've missed their medication for several days at this point. Of course they will develop drug resistance!" Ganesh says.

Ganesh believes the work of TB Champions should not stop. "There are so many areas in just Mumbai where people live in cramped spaces without any ventilation – conditions where TB can spread quickly. If we want to eradicate TB, we need to reach out to all of these people. And I'm willing to do this work in order for that to happen."

## SHANU



"There are some government hospitals in Delhi today that have separate queues and bathrooms for trans persons," says 29-yearold Shanu, a B.Com graduate and a TB Champion, "It's important that the same facilities are provided for transgender persons, LGBTQIA++ persons, at TB hospitals as well."

Shanu is a transgender woman who has worked corporate jobs and has had to quit because of discrimination. As a TB survivor and a person with HIV, she believes she is an ideal candidate to motivate persons with TB to complete their treatment and recover fully. "I have faced a lot of challenges to get where I am today. I have faced a lot of stigma and discrimination both as a transgender person and when I had TB. I have faced sexual harassment as a child from my own family member. I have faced discrimination at the workplace. I have done sex work for survival. If I can survive all this – then so can others," Shanu says. And therefore, when she got the opportunity to become a TB Champion with REACH, Shanu was happy to take it on. After receiving training in Delhi, Shanu worked with trans persons as well as the larger population on TB prevention, and on helping individuals with TB get the relief that is due to them through various government schemes. She has ensured that transgender persons get their documents in place, so that they can apply for various benefits including the Rs 500 per month that persons with TB receive from the government. She has helped several trans persons get a TB diagnosis and get on a treatment routine as well.

"The thing though is, everyone faces stigma in the system," Shanu says, "especially transgender persons. When the workers at the hospital see us, they dismiss our needs and prioritise cis-het persons. There are no separate queues for LGBTQIA++ persons, so there is no equal opportunity to getting ahead in the line."

Further, the healthcare providers are insensitive to persons who are diagnosed with both TB and HIV, Shanu says – especially when they're LGBTQIA++ identified. "Take the case of my friend. He's queer and he was HIV positive – the doctors, without any sensitivity, told his family that he cannot marry and that he can never have children. They did not provide them with any understanding, instead they indulged in scaremongering," Shanu recalls.

Which is why, she says, there has to be consistent advocacy among healthcare workers – about HIV, about TB, and about LGBTQIA++ identities. Another issue, Shanu points out, is the window during which tests are available in TB hospitals. The testing closes by 12 noon – however for transgender persons who are engaged in traditional occupations of Doli-Badhai, it is difficult to come to the hospital during these hours. "I think they should increase by at least a few hours so that more at-risk people are willing to get themselves tested," she says.

Shanu believes that any advocacy with LGBTQIA++ communities – especially trans persons – has to be long term. "They don't

trust NGOs coming in with different things, because they feel they're being used by them. People and organisations simply come and go. If we are serious about addressing TB, engagements like REACH's work with TB Champions should happen for much longer. The community will trust us if they see some benefit in what we're doing," Shanu says, "I'm willing to do a lot more to make sure my community is safe from TB. I continue to do the work of a TB Champion and help people on my own – I'm waiting for opportunities to do it on a larger scale."



#### **About FIND**

FIND accelerates equitable access to reliable diagnosis around the world. We are working to close critical testing gaps that leave people at risk from preventable and treatable illnesses, enable effective disease surveillance, and build sustainable, resilient health systems. In partnership with countries, WHO and other global health agencies, we are driving progress towards global health security and universal health coverage. We are a WHO Collaborating Centre for Laboratory Strengthening and Diagnostic Technology Evaluation. We established our presence in India in 2007, and today are the only non-profit organization registered in the country that is solely devoted to improving diagnostic testing. For more information, please visit www.finddx.org.

#### **About REACH**

REACH is an India-based non-profit organisation founded in 1998 in Chennai. For over 25 years, through an unrelenting focus on TB, REACH has demonstrated capacity to engage diverse stakeholders including the private sector, TB-affected communities, industry leaders, elected representatives, and the media. REACH has been a key partner and leader in the fight against TB in India, working closely with the TB programme and engaging various stakeholders including the private sector, affected communities, industries, the media, and other important stakeholders in TB elimination. Through the TB Call to Action Project supported by USAID, REACH first developed and tested the TB survivor to TB Champion model in six states (2016 - 2020), demonstrating that community willingness to engage with TB services can be greatly enhanced through the efforts of empowered TB Champions. Through the Unite To ACT Project, the training and engagement of TB Champions have been expanded and scaled up across India.



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