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Tuberculosis and Disability

Rapid Assessment Report

India (2023)



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Message from NTEP



सत्यमेव जयते



आज़ादी का
अमृत महोत्सव

Dr. Rajendra P. Joshi
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
ddgtb-mohfw@gov.in
011-21400941

Message from Central TB Division

In March 2023, the Honourable Prime Minister of India reiterated the nation's commitment to achieving a TB-free India, launching several new initiatives to build on our successes and achievements to date. The TB response in India has been swift to recover from the impact of the COVID-19 pandemic, with an annual case notification of over 24 lakhs, higher than the pre-pandemic high in 2019.

To achieve our ambitious goal, the Central TB Division is working in mission mode through a multi-pronged approach. We have rolled out new strategies, adopted new tools and introduced new regimens, all intended to achieve our vision of providing high-quality, person-centred services. This includes a focus on those most vulnerable and at risk, including people with disabilities, who need clinical and social support to seek timely care and be cured of TB.

An estimated 2% of India's population lives with disabilities of various kinds, including physical and mental disabilities. In recent years, the Govt. of India has rolled out several schemes for people with disabilities, to ensure their access to education, health and various social support mechanisms. There is a need for a greater focus and understanding of how disabilities intersect with infectious diseases like TB, and I am very pleased that REACH has undertaken this rapid assessment, with support from USAID.

The long-term impact of TB on the physical and emotional health of individuals is well documented. The National TB Elimination Programme has enhanced its focus on post-treatment follow-up, with the objective of identifying those with recurrent symptoms and in ill-health, and linking them to appropriate care. We also need to understand the nature and extent of disabilities that people may develop while on TB treatment and ensure supportive rehabilitation mechanisms, through multi-sectoral action.

I am delighted that India is one of the first countries to undertake a rapid assessment on TB and Disability, bringing together epidemiological, clinical and socio-economic perspectives to construct a clear path forward for this important aspect of the TB response. This report on TB and Disability features the inputs of TB technical experts, disability experts, programme implementors, TB survivors and people with disabilities, and as such, reflects ground realities that we are committed to addressing.

On behalf of the Central TB Division, I congratulate REACH and thank all those who have provided their valuable inputs to this assessment. We look forward to working together to develop and implement robust strategies to focus on the linkages between tuberculosis and disability and prioritise the needs of people with disabilities.

(Dr. Rajendra P Joshi)

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The development of this Publication is made possible by the support of the American People through the United States Agency for International Development (USAID). The contents of this Publication are the sole responsibility of REACH and do not necessarily reflect the views of USAID or the United States Government.

Message from USAID/India

For several decades, the United States and India have worked together to combat tuberculosis (TB) by improving patient-centered diagnosis, treatment, and prevention. The United States Agency for International Development (USAID) is proud to work with the National TB Elimination Programme (NTEP) in India, supporting the Government of India's goal to end TB, while enhancing global health security.

Towards this goal, USAID is actively implementing the ALLIES (Accountability Leadership by Local Communities for Inclusive, Enabling Services) project to assist the NTEP in India. Our approach encompasses community-led actions, including the implementation of the Community Accountability Framework, and focuses on TB in the elderly and individuals with disabilities.

This report presents USAID's findings from a rapid assessment that explored the intersection of TB and Disability—a first-of-its-kind study in India. While it is widely recognized that TB can have long-term effects on individuals, there has been limited global attention devoted to understanding the specific nature of long-term disabilities caused by TB and addressing them promptly. Insufficient information exists on how TB affects people with disabilities, including their access to healthcare services, experiences with TB, and the quality of care they receive. USAID's Rapid Assessment aims to bridge this critical knowledge gap and shed light on the issue.

These findings will support the development and implementation of equitable and inclusive strategies that cater to the needs of individuals with disabilities. Equipped with this knowledge, USAID, along with its partners, can create an environment where individuals receive the necessary support and care they need following recovery from TB.

Aligned with our commitment to diversity, equity, inclusion and accessibility, USAID proudly supports this assessment and commends REACH for raising awareness on the complex intersections of TB and disability. USAID remains committed to supporting the Government of India in their nationwide efforts to eliminate TB, striving for a future where everyone, regardless of background or abilities, can live free from the burden of TB.

Sangita Patel
Ms. Sangita Patel
Director, Health Office
USAID/India

Message from REACH

Tuberculosis (TB) has a disproportionate impact on persons with disabilities, accentuating their health challenges and creating additional barriers to accessing proper care such as reduced access to health services, limited awareness to information, communication challenges, stigmatisation, and discrimination. Furthermore, TB can lead to disability or worsen existing disabilities, creating a vicious cycle of challenges for those affected and their families.

For the last 25 years, REACH has been working with TB-affected communities to provide holistic and personalised care and support, besides addressing other underlying issues to ensure their mental and emotional well-being. Our interventions are deeply rooted in equity and inclusivity; we want to ensure that the voices of those most vulnerable are heard, their rights are protected, and their health is prioritised.

In our pursuit of a TB-free India, we recognise the importance of leaving no one behind. And therefore, REACH takes great pride in presenting this rapid assessment which paints a vivid picture of the complex interplay between TB and disability. The report reaffirms that long-term and short-term disabilities are a potential outcome of TB and lists comprehensive recommendations that fill a critical knowledge gap towards addressing the physical, economic and psychosocial needs of TB survivors with disabilities.

By prioritising their needs, advocating for change, and adopting an inclusive approach, we can together create a comprehensive healthcare system that is more accessible, data-driven and prioritises person-centred care for people with disabilities who are diagnosed with TB.

We would like to express our deepest gratitude to all senior officials, technical experts, NTEP teams, TB Champions, TB survivors, people on treatment for TB, people with disabilities and their family members who shared their experiences and insights for this assessment.

We are grateful to USAID for their constant support to undertake this rapid assessment, as part of the Accountability Leadership by Local Communities for Inclusive, Enabling Services (ALLIES) project.

Finally, we are grateful to the Central TB Division team for their steadfast leadership and guidance. We are deeply committed to continuing to work together to achieve our collective dream of a TB-free India.



Dr. Ramya Ananthakrishnan

Director, REACH

Acknowledgements

This rapid assessment was conceptualised by Dr. Ramya Ananthakrishnan, Director, REACH and Ms. Anupama Srinivasan, Asst. Director, REACH and authored by Ms. Nivedita Krishna, Ms. Krithika Sambasivan, Ms. Anagha Sasidharan, and Ms. Mansvini Ranganathan of Pacta, with support and inputs from Mr. Subrat Mohanty, Sr. Advisor and Project Lead, REACH and Dr. Sripriya Pandurangan, Deputy Project Lead, REACH.

We thank all senior officials and programme implementers who accepted our request to be interviewed for this rapid assessment and provided their valuable time and inputs, including Dr. Sanjay Kumar Mattoo, Additional Deputy Director General, Central TB Division, Ministry of Health and Family Welfare, Govt. of India; State TB Officers, WHO Consultants and other NTEP staff. We are very grateful to the following technical experts for their participation in this rapid assessment: Dr. Yogesh Jain, public health specialist; Dr. Beena Thomas, retired Scientist, National Institute of Research in Tuberculosis; Dr. Ashwani Khanna, former State TB Officer, New Delhi; Dr. Anindya Mitra, Director, STDC, Jharkhand; Ms. Prachi Shukla, Country Director, World Health Partners; Ms. Reena Mohanty, Shanta Memorial Rehabilitation Centre, Odisha; Ms. Vaishnavi Jayakumar, Disability advocate and Founder, The Banyan; Ms. Smitha Sadasivan, Disability advocate; Ms. Nandita Venkatesan, journalist, TB survivor and advocate; and several senior private practitioners, clinicians and disability advocates who provided critical inputs.

We are deeply grateful to all the TB Champions, TB survivors, people on treatment for TB, people with disabilities and their family members who shared their experiences and insights for this assessment.

We express our sincere gratitude to the USAID/India team, including Ms. Sangita Patel, Director, Health Office; Dr Reuben Swamickan, Chief, Infectious Diseases Division; and Ms. Amrita Goswami, Development Assistance Specialist for their support, technical guidance and the opportunity to undertake this rapid assessment, as part of the Accountability Leadership by Local Communities for Inclusive, Enabling Services (ALLIES) project.

Finally, we gratefully acknowledge the continued support and guidance of the Central TB Division and senior officials at the Ministry of Health and Family Welfare, Govt. of India.

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Executive Summary

In the 21st century, Tuberculosis (TB) remains a global public health crisis and a major health security threat. In India, which bears over a quarter of the global TB burden¹, high-level political commitment to achieve TB elimination has resulted in the introduction and adoption of new diagnostic tools, new treatment regimens, person-centred policies and engagement of affected communities.

TB is a complex disease; it affects and is affected by multiple clinical and social vulnerabilities including other comorbidities, gender, economic status, housing, access to health etc. One such vulnerability that has been little discussed is disability, which has both clinical and social dimensions. The intersection of TB and disability is two-fold:

- i) an individual's disabilities could accentuate their vulnerability to TB and hinder access to TB services. Existing disabilities could mask TB symptoms and result in delayed diagnosis.
- ii) an individual could develop a disability – or multiple disabilities – during or as a result of TB treatment. This could mean that a person cured of TB has to live with a life-long disability.

In general, people with disabilities remain among the most marginalised groups in India. Health and health outcomes remain poor. Inaccessible healthcare further impedes access and adversely impacts health-seeking behaviour. In the context of TB and people with disabilities, there is a lack of knowledge on how TB plays out in terms of health outcomes and access to healthcare. Therefore, a deeper understanding is needed to serve persons with disabilities better through the TB programme. This includes the need for data, which drives evidence-based policy change. However, data on access to healthcare for people with disabilities is either entirely missing or inadequate, as is data on people with disabilities and TB.

This report describes the complex interplay of TB and disability, from a clinical, social and economic lens, including aspects such as mental health, gender, stigma, livelihood, nutrition etc. The impact of each of these dimensions is magnified for people with disabilities. From the perspective of people with disabilities, the health system remains challenging to access, with few personalised support mechanisms in place. This is true for the TB care cascade as well, which people with disabilities need support to navigate.

Through an analysis of first-hand accounts from TB survivors, the rapid assessment report establishes that the impact of TB extends beyond mortality and morbidity, and needs to be understood from the lens of years lived with disabilities and quality of life measures. For TB survivors who have acquired disabilities during or post TB, life has irretrievably changed. Strengthening long-term comprehensive care and making available physical and social rehabilitation for TB survivors is an essential element of post-treatment follow-up. Identifying and acknowledging disability as an outcome of TB is the first essential step.

This rapid assessment is a first step towards understanding the contours of this complex intersection, through an extensive literature review and qualitative interviews with communities, clinicians and policymakers. This report describes the key findings from this exercise in two sections: findings from the desk review and findings from the qualitative interviews. This is followed by a series of specific recommendations, at the structural, policy and programmatic levels, to provide better quality care to people with disabilities and TB survivors who develop disabilities. Overall, the findings and recommendations underscore the urgent need to pay greater attention to the linkages between TB and disability. More research is required to strengthen our understanding and steer tangible change for people with TB and disabilities. It is incumbent upon all of us – policymakers, public health specialists, programme designers, implementers, clinicians, community leaders – to reimagine our public health system and the response to TB in India from a disability-inclusive lens.

1. World Health Organization. Global tuberculosis report 2021 [Internet]. World Health Organization. 2021 Oct 14 [Cited 2023 Jan 16]. Available from: <https://www.who.int/publications-detail-redirect/9789240037021>

1. Introduction and Rationale

In the 21st century, Tuberculosis (TB) remains a global public health crisis and a major health security threat. The last decade has seen a growing acknowledgement of the extent of the challenge that TB poses, and a considerable expansion, in both scope and scale, of the global TB response. In India, which bears 26% of the global TB burden², high-level political commitment to achieve TB elimination has resulted in the introduction and adoption of new diagnostic tools, new regimens, person-centred policies and engagement of affected communities.

TB is a complex disease, both impacting and impacted by multiple clinical and social vulnerabilities including other comorbidities, gender, economic status, housing, access to health etc. One such vulnerability that has been little discussed is disability, which has both clinical and social dimensions. The intersection of TB and disability is two-fold:

- iii) an individual's disabilities could accentuate their vulnerability to TB and hinder access to TB services. Existing disabilities could mask TB symptoms and result in delayed diagnosis.
- iv) an individual could develop a disability (or multiple disabilities) during or as a result of TB treatment, through adverse reactions to anti-TB drugs. This could mean that a person cured of TB has to live with a life-long disability.

The intersectionality between tuberculosis and disability, whether as a pre-existing condition prior to contracting TB or as a consequence of TB, is largely understudied. This rapid assessment is a first step towards understanding the contours of this intersection, through an extensive literature review and qualitative interviews with communities, clinicians and policymakers. The findings of this assessment underscore the urgent need to pay greater attention to the linkages between TB and disability.

This rapid assessment was designed and undertaken in response to the following key factors:

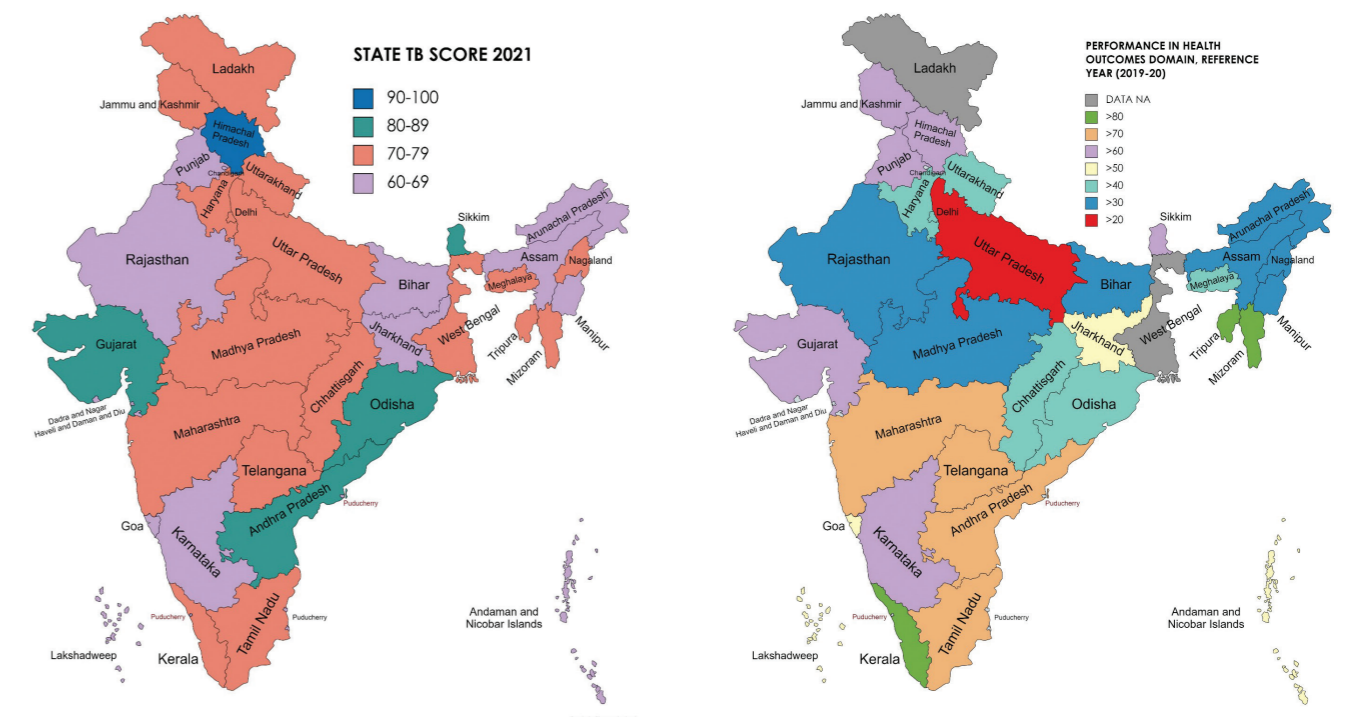
1. Little attention paid to TB-related disabilities and hence, post-TB Quality of Life (QoL) The impact of TB beyond mortality and morbidity has not been understood from the lens of years lived with disabilities and quality of life measures in India (from a social constructivism lens). Little attention has been paid to understanding the nature of disabilities caused due to TB, the years lost to disabilities, and HRQoL and its determining factors. There has not been much focus⁶ on the long-term care or appropriate responses such as comprehensive treatment plans^{4,3} to enhance QoL, thus leaving TB survivors to cope with the morbidity sequelae and its socio-economic impact on their own. There is a need for a systematic mechanism to identify, measure and address disabilities caused by TB and better understand QoL of TB survivors.⁶

2. Lack of literature on experiences of people with disabilities in the TB care cascade People with disabilities remain among the most marginalised groups in India, with poor health and health outcomes. Many people with disabilities experience stigma, poverty, and other socio-economic barriers. Inaccessible healthcare adds further complications to their health seeking behaviours. In the context of TB and persons with disabilities, there is a lack of evidence on how TB plays out in terms of health outcomes and access to healthcare. Furthermore, persons with disabilities are not accounted for or considered as a vulnerable population for TB specifically. Therefore, a deeper understanding is needed to serve persons with disabilities better through the TB programme.

3. Lack of robust data at the intersection of TB, disability and access to healthcare Data drives evidence-based policy. The TB programme has a data rich ecosystem but does not currently collect or analyse data on disabilities. Overall, within the health system, data on access to healthcare for vulnerable populations such as persons with disabilities is lacking. Robust operational databases are important to deliver targeted healthcare. At present, the National TB Elimination Programme or NTEP does not collect disaggregated data on persons with acquired long-term impairments caused due to TB. Those affected are not linked to long-term rehabilitation care facilities. Budgetary allocations for rehabilitation are required, along with mechanisms for availing TB-related disability pensions through coordinated efforts with the Ministry of Social Justice and Empowerment to ensure access to existing services and schemes offered to persons with disabilities⁹⁹.

The three maps represent three factors that are critical to better understanding the TB-disability intersection lens. The first map represents the success of the TB programme by state i.e., the success of treatment completion and the notification rates. Higher TB scores indicate better performance. The second map shows state-wise health indices. In other words, the map reveals

Diagram 1: Representation of intersectional gaps in data. State TB scores,⁴ health indices of states⁵ and prevalence of persons with disabilities⁶



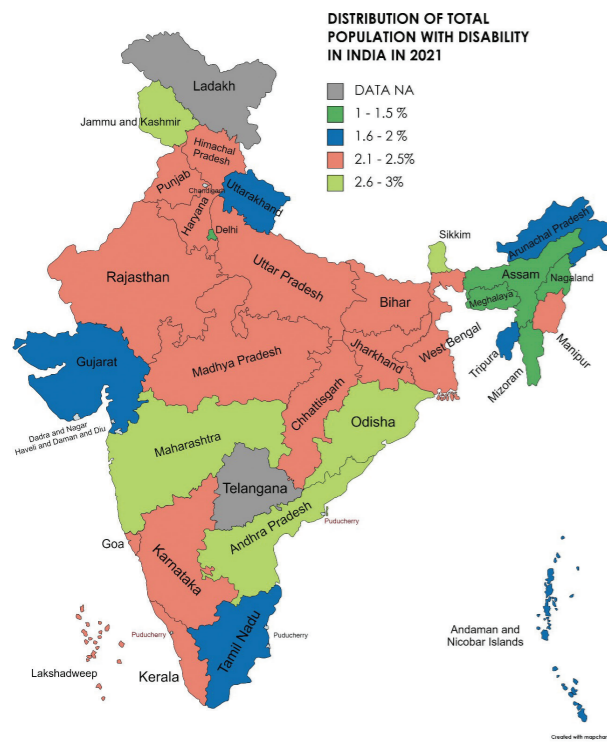
4. National Health Mission, Ministry of Health and Family Welfare. Health Atlas of Aspirational Districts [Internet]. Ministry of Health and Family Welfare. 2018 April [cited 2023 Jan 16]. Available from: <https://tbcindia.gov.in/showfile.php?lid=3635>.

5. The World Bank, Niti Aayog, Ministry of Health and Family Welfare. Health states progressive India. Report on the ranks of states and union territories. Health index round IV 2019-20 [Internet]. Ministry of Health and Family Welfare. 2021 December 24 [cited 2023 Jan 16]. Available from: https://www.niti.gov.in/sites/default/files/2021-12/NITI-WB_Health_Index_Report_24-12-21.pdf

6. C-30 Disabled population by type of disability, type of households and sex (India & States/UTs) [Internet]. Office of the Registrar General & Census Commissioner, India. 2011 [cited 2023 Jan 16]. Available from: <https://censusindia.gov.in/census.website/data/census-tables>.

2. World Health Organization. Global tuberculosis report 2021 [Internet]. World Health Organization. 2021 Oct 14 [Cited 2023 Jan 16]. Available from: <https://www.who.int/publications-detail-redirect/9789240037021>

3. Shukla K. TB often leaves its victims disabled, and India has no help for them [Internet]. The Wire Science. 2020 Mar 3 [cited 2022 Aug 14]. Available from: <https://science.thewire.in/health/tuberculosis-disabilities-ntep-drug-resistance-assistive-devices-uncrpd/>.



the position and effectiveness of the healthcare system in achieving good health outcomes in the population of each state across India. Here too, the higher the score, the better the healthcare system, hence better the health outcomes. The third map shows state-wise prevalence and distribution of persons with disabilities. It is important to note here that there is a lack of intersectional data between disability and health outcomes in general, and disability and TB specifically. There is a clear need for an integrated interoperable dataset that would help answer critical policy questions and improve our understanding of this complex relationship between TB and disability.

2. About this Assessment

Methodology

The purpose of this rapid assessment on TB and disability was to 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
- Challenges for people with disabilities in accessing TB services

2.1 Design Overview

A qualitative rapid assessment was conducted to understand the landscape of the long-term sequelae of TB and the impact of TB in persons with disabilities. A rapid assessment is an established qualitative enquiry method to quickly develop a preliminary understanding of a situation⁷; in this case, TB and Disability. As part of the process, an exhaustive desk review was undertaken, followed by in-depth semi-structured interviews with four different types of stakeholders. Thematic analysis was used to uncover patterns in the qualitative data.

2.2 Participants

Stakeholders were categorised into four groups namely, people with TB and/or disability, TB programme implementers/policymakers and TB and/or disability experts.

- People with TB and/or disabilities
 - Persons with disability who have a history of TB (n=13)
 - Persons who have had TB and now suffering long-term sequelae of disease (n=5)
- TB programme implementers/policymakers (n=6)
 - Policymakers including government officials from the Central TB Division, National TB Elimination Programme and National Health Mission under the Ministry of Health and Family Welfare
 - Non-Government Organisations (NGOs)/Civil Society Organisations (CSOs) working in the sector
- TB Experts/Disability Experts (n=13)
 - TB experts – researchers/scientists from National Institute for Research in TB (NIRT), Indian Council of Medical Research (ICMR), NGOs/CSOs in the sector
 - Doctors/physicians – TB
 - NGOs/CSOs operating Rehabilitation Centres and Disability Advocates

2.3 Sample Population Demographics

Our sample population interviews consisted of 18 interviews in total. Of this, 13 people are TB survivors or those on treatment, all of whom developed either temporary or permanent disabilities post TB treatment. We have referred to these people as people with TB or 'PwTB' in this section. The other five participants were persons with disabilities who contracted tuberculosis. Since these participants had existing disabilities prior to contracting TB, we refer to them as people with disabilities or 'PwD'. The age range of the interviewees was from 16 years to 55 years. The majority of those we spoke to were from poorer socio-economic backgrounds. A detailed description of individual participants can be found in Annexure 2.

Other Stakeholders: We interviewed 19 experts in the fields of TB and disability including clinicians, TB programme implementers, policymakers and disability experts, among others.

2.4 Recruitment

A convenience sample was chosen in each of the groups. The sample population group was recruited through REACH's networks. These were persons who were associated with REACH during or after treatment. Other stakeholders were recruited based on REACH and Pacta's networks. Snowballing methodology was adopted, where needed, to recruit additional participants who could provide insights into the issue.

Participants were recruited from various parts of India. An initial contact was made by the field staff and a recorded message from the Pacta team was shared with potential participants. When participants agreed to take part, a time for an interview was scheduled based on mutual convenience.

Other stakeholders including experts, implementers, and policymakers were contacted via email by Pacta/REACH. Once participants agreed to take part, an interview session was scheduled based on mutual convenience.

2.5 Data Collection Instruments

Semi-structured interview questionnaires were used to answer research objectives. Questionnaires were developed for individual stakeholders based on current literature and expertise consultations.

7. <https://www.sciencedirect.com/topics/medicine-and-dentistry/rapid-assessment#:~:text=rapid%20assessment%20is%20defined%20as,situation%20from%20the%20insider's%20perspective.>

Each of the four questionnaires contained about 12-15 questions (Annexure 3). Questionnaires were translated into Hindi and Tamil for the sample population interviews. For participants in the sample population group who had a loss of hearing due to TB, questionnaires were translated into Hindi and sent via WhatsApp—answers were received as text.

Demographic data for the sample population were collected as part of the interview protocol. Pertinent information on other stakeholders were sought through CVs, organisation web pages, and/or social media sites such as LinkedIn.

2.6 Procedure for Data Collection

Interviews for the sample population were conducted via phone calls which were recorded after taking consent. Participants were briefed about the purpose of the assessment and their rights. Interviews took place for 20-30 mins in the preferred language of the participant. All recordings were translated and transcribed manually for further analysis.

Interviews were set up based on the convenience of the other stakeholders. All interviews were held virtually via Google Meet. Participants were briefed about the purpose of the call and consent to record the conversation was sought before the start of the session. All interviews lasted about 45-60 mins. Interviews were then transcribed using Otter.ai software. It took about one-and-a-half to two months to complete the data collection process.

2.7 Ethical Considerations

As part of the data collection protocol and due to the sensitive nature of the topic, ethical considerations such as non-disclosure, de-identification of identifiable information, confidentiality, and protected storage of data was maintained. All data was accessed only by the research team.

2.8 Analysis

A thematic analysis was used to uncover patterns in the data. Interviews were transcribed verbatim. Transcripts were read for open coded. Codes were categorised across participants and themes were generated through axial coding for each of the groups. Sub-themes were identified under each theme where present. Themes were generated based on the research question and the objectives of the rapid assessment.

2.9 Limitations of the assessment

This rapid assessment of the current state of TB and Disability is not intended to be a research study. As such, it is not based on statistically significant data sampling methods. The assessment is intended to provide a high-level overview and perspective into an important dimension of the TB response. In addition, interviews, particularly those with people with TB and people with disabilities, were done over calls, which made it challenging, at least initially, to build a rapport with interviewees. However, the researchers ensured that interviews were conducted in the language that was most comfortable to the interviewee. This allowed the interviewees to develop a level of trust with the interviewer, resulting in more candid conversations.

3. Literature Review

3.1 Tuberculosis

Tuberculosis is a global infectious disease, treatable and curable, but a leading cause of mortality and morbidity worldwide. The Global End TB Strategy (2020) and commitments by various governments, including India, to achieve TB elimination have resulted in tangible actions over the last few years.

TB presents in various forms and the characteristics of the disease vary based on its presentation. TB most commonly affects the lungs (pulmonary) and has a higher incidence among adults. TB also manifests in children and adolescents and in high-risk individuals such as those with HIV/AIDS (who need urgent attention); as latent TB, drug-sensitive and drug-resistant, and extrapulmonary⁸. The most common symptoms of pulmonary TB include a cough for over two weeks, unexplained weight loss, loss of appetite, night sweats, fever, and fatigue.⁹ Symptoms of extrapulmonary TB vary based on the area infected.⁷ People with HIV are at greater risk of acquiring TB and mortality rates are higher in these individuals.³

Globally, approximately 10.6 million people had TB in 2021 of which, six million were men, 3.4 million women, and 1.2 million children.³ Countries in South Asia – also considered Low-and Middle-Income Countries¹⁰ (LMICs) including India, Bangladesh, Pakistan have a high incidence of TB and are termed as high-burden countries.² High burden countries account for 87% (incidence rates) of the cases worldwide with India contributing to the largest number of cases (28% in 2021¹¹).³ South Asia also accounts for the highest number of children with TB (350,000 cases).¹² According to the recent National Prevalence Survey, the prevalence rates of active pulmonary TB between 2019-21 in India were reported to be 316 cases/lakh population (>15 years of age) and 312 cases/lakh population after adjusting for type of TB and age of prevalence with Delhi reporting the highest burden of disease (534/lakh population; 747/lakh population (adjusted)¹³. Prevalence rates were highest among the elderly (>65 years), higher in males compared to females, among people who use alcohol, those who smoke, have diabetes and among the malnourished.^{10,12}

TB affects multiple spheres of an individual's life. TB primarily affects those from lower socio-economic backgrounds or multidimensionally poor people¹⁴, leaving a high socio-economic burden on the person affected and their families. In a study to assess the impact of TB on employment, education and economic status of Indian families, authors found that an average of 83 days of employment were lost and debts due to medical interventions for TB ranged between Rs. 2,000-5,000 for six months, including both direct and indirect costs.¹⁵

Social determinants play a critical role in vulnerability to TB in India. One of the important social determinants that enhances vulnerabilities in the context of TB is stigma. Stigma creates a

8. Brown J, Capocci S, Smith C, Morris S, Abubakar I, Lipman M. Health status and quality of life in tuberculosis. *International Journal of Infectious Diseases*. 2015 Mar;32:68–75. doi: 10.1016/j.ijid.2014.12.045. PubMed PMID: 25809759.

9. Diagnosis of Tuberculosis Disease [Internet]. Centers for Disease Control and Prevention; 2016 May 4 [cited 2022 Aug 3]. Available from: [https://www.cdc.gov/tb/publications/factsheets/testing/diagnosis.htm#:~:text=Additional%20tests%20are%20required%20to,\(induration\)%20on%20the%20arm](https://www.cdc.gov/tb/publications/factsheets/testing/diagnosis.htm#:~:text=Additional%20tests%20are%20required%20to,(induration)%20on%20the%20arm).

10. The world by income and region [Internet]. The World Bank. 2021 [cited 2022 Aug 1]. Available from: <https://datatopics.worldbank.org/world-development-indicators/the-world-by-income-and-region.html#:~:text=The%20World%20Bank%20classifies%20economies,%20middle%20and%20high%20income>.

11. World Health Organisation. Global Tuberculosis Report 2022 [Internet]. Geneva: World Health Organisation; 2022 [cited 2022 Sep 17]. Available from: <https://www.who.int/publications/i/item/9789240061729>.

12. Tuberculosis [Internet]. UNICEF. 2019 Oct [cited 2022 Aug 3]. Available from: <https://data.unicef.org/topic/child-health/tuberculosis/#:~:text=Only%207.1%20per%20cent%20of,cent%20of%20all%20tuberculosis%20cases>.

13. Indian Council of Medical Research (ICMR). National Institute for Research in Tuberculosis (NIRT), Ministry of Health and Family Welfare, Central TB Division (CTD), National Tuberculosis Elimination Program. National TB Prevalence Survey India 2019-2021 - Summary Report [Internet]. Ministry of Health and Family Welfare; 2022 [cited 2022 Sep 17]. Available from: <https://tbcindia.gov.in/showfile.php?lid=3659>

multitude of barriers for people with TB and can accentuate existing vulnerabilities. For example, a transwoman with TB faces the dual burden of stigma associated with their transgender identity and with the TB disease. The same is true for people with disabilities. Stigma can influence health seeking behaviours in a negative way – increasing the probability of delay in diagnosis and treatment and reducing adherence to the treatment regimen.¹⁶

Other vulnerabilities include age, gender, place of residence (socio-demographic factors) and health determinants of a person. Women and gender minorities, children, people from tribal communities¹⁷, people with HIV/AIDS, smokers, people who use alcohol, diabetics, and malnourished individuals are vulnerable to acquiring TB and are acknowledged as priority populations under India's TB programme.¹⁸ Priority populations are defined as “disadvantaged groups of people as compared to others, due to their reduced access to medical services and the underlying determinants of health”.⁶

3.2. Disability

According to the United Nations Convention for Rights of Persons with Disabilities (UNCRPD) 2007, disability is defined as “persons with disabilities including those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.¹⁹ This definition has been criticised for its limited view on disability. It fails to include the lived experiences of persons with disabilities from the perspective of their functional interaction with the environment and the social context they live in.²⁰ Hence, the International Classification for Functioning, Disability, and Health (ICF) has proposed a definition entailing different aspects of the person's life. The proposed definition reads “Disability is a difficulty in functioning at the body, person, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors”.²⁹

As a construct, disability is now viewed from a social lens. As per the social constructivism lens, “rather than one universal experience of disability, this view acknowledges that disabled people have different experiences across time and cultures, and ideas about what disability means and who is disabled are defined by humans.”²¹ When the social lens is applied to healthcare delivery and medical experiences of persons with disabilities and acquired diseases in India, there emerges a gap in our understanding of their individualistic experiences. This hinders person-centred care for persons with disabilities.

Further, the Rights of Persons with Disabilities (RPWD) Act of 2016 aims to protect the rights of persons with disabilities in all aspects of their lives.²² The Act lists 21 disabilities. However, a deeper examination of the law shows a broad approach to the provision of rights for persons with disabilities²³ that does not fully reflect the social, cultural, and economic complexities associated with specific types of disabilities and diseases causing disabilities. For example, in the context of access to justice for persons with disabilities, each person would need specific accommodations based on the type of disability. Court systems are not geared towards such individualistic needs. This would hold true for access to healthcare as well. Another challenge with the current socio-legal definition of disability is that the law recognises and rewards benefits to those with benchmark disabilities i.e., with >40% disabilities, leaving out those who possess disability at or below 40%.²⁴ Thus, there is a need for a more social constructivist view on disability in every sphere of the individual's life, with an understanding of each disability, their aetiology, its presentations, and the individualised care required.

While a more social constructivist view in mainstreaming disability is important, there are some basic challenges in India such as understanding the number of people with disabilities. For policy interventions to make a meaningful impact in improving the quality of life of those with disabilities, it is crucial to have accurate prevalence data on people with disability. Reporting of disability statistics is a challenge in India, compared to world standards²⁵ due to lack of standardised definitions and measures of disabilities (Census of India²⁶ vs. National Sample Survey Office - NSSO²⁷), stigma, under- or over-diagnosis, distributed and diversified storage of data and lack of interoperability of the databases.²⁸ The NSSO 2018 reported that the total number of people with disability in India was close to 30 million, which is about 2.2% of the population. The Census 2011 projected a similar percentage of the population at approximately 26.8 million people. However, the National Family Health Survey (NFHS), 2019-21 showed persons with disability constituted only 1% of the population. According to the World Bank, 2007, persons with disabilities accounted for 4-8% of the population in India (around 40-90 million people). The variations in data and lack of consistent updated data in the disability sector are a critical impediment to service delivery and implementation of policy measures. This hinders the efficient distribution of and access to essential government schemes, entitlements or benefits and aid for persons with disabilities – an important aspect of accessibility, adaptability, acceptability and thus, inclusivity.²⁹ While there are measures proposed by the government to increase robust data in the disability sector through adequate data collection methods and digitisation of data across different departments, including increasing their interoperability as mentioned in the latest draft Disability Policy, 2022, there is still a long way to go in mainstreaming disability in different policies. Moreover, a bottom-up approach is important to understand the challenges of persons with disabilities in access to healthcare to incorporate policy-level changes.

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3.3 Intersection of TB and Disability

There is an increasing need to have diverse, equitable and inclusive social systems on a global scale. Global conventions and country policies are moving in this direction. Attention is now being given to intersectional relationships between various demographic, health, economic and social determinants of a person and their ability to access fair and quality services. However, there is a need to strengthen such policies through an on-the-ground approach and practical understanding of the challenges. Prior research at the intersection of TB and disability at the global level has been sparse. In India, there is little evidence on the intersection of people with disabilities and public health, generally. In this section, we highlight the intersectional relationship between disability and TB, based on available literature.

Tuberculosis and Disability: Impact of the Disease

There is growing acknowledgement that the aftermath of TB is not just cure or mortality (given its heterogeneity) but morbidity, poverty, and suffering among those who contract it.³⁰ In a recent systematic review³¹ to understand the long-term medical/clinical effects of TB, authors included 131 studies from 49 countries (with a majority of studies done in India) and found mental health conditions (23.1%), respiratory (20.7%), musculoskeletal (17.1%), hearing (14.5%), visual (9.8%), renal (5.7%), and neurological (1.6%) impairments to be most commonly occurring post TB. In LMICs, neurological impairments (25.6%) were reported to be the highest among post TB complications compared to respiratory impairments (61.2%) and mental health conditions (42.0%) in high-income countries. Those with drug resistant TB had respiratory (58.7%) and neurological (37.2%) complications, hearing impairments (25.0%), and mental health conditions (26.0%).

Post-TB pulmonary complications have been reported worldwide but are grossly underestimated in high-burden countries.^{42,43} Complications such as decreased lung functioning and capacity and exercise tolerance reduce the quality of life in these individuals, particularly in those with prolonged disease and more severe baseline X-rays.^{41,42} In India, a study done to understand the long-term effects of pulmonary TB found that where there was delay in diagnosis there was a direct relationship to the severity of airway damages and the chance of residual respiratory disabilities.⁴⁴ This was more frequently seen in men and the elderly (between ages of 61-70 years).⁴³

In a study done to understand the effects of extrapulmonary TB in children in Greece, authors found that children with co-infection of meningitis developed long-term sequelae of neurological disabilities. Young age and delay in administering appropriate treatment were found to be reasons for developing serious complications post TB.⁴⁵ In addition, poverty, HIV status, access to medical treatment, and social disruptions played a critical role in development of long-term TB-related complications in children.^{44,36} Overall, social and economic determinants such as poverty, housing, greater out-of-pocket expenditure, income, nutrition status, and access to clean fuel³⁷ as well

as health-related risk factors such as undernutrition, HIV status, smoking and alcohol use put individuals at higher-risk of contracting the disease and hence poorer outcomes.³⁷

HIV/AIDS leads to long-term disabilities due to complex treatments and susceptibility to other fatal infections or diseases.^{38,39} When present along with TB it leads to high risk of mortality, morbidity, and negative social consequences.³ 90% of those with a co-infection of HIV and TB in India were found to be in their productive years (15-49 years) contributing actively to the economy.⁴⁰ Mortality rates are high in this age group leading to greater socio-economic burden for the country.⁴⁹

Disabilities due to TB can be caused due to the disease process itself i.e., based on the site of affection or due to the side-effects of drugs. While some of the physical impairments such as neurological spinal impairments lead to permanent disabilities, the side-effects of certain medications lead to temporary or permanent disabilities.⁴⁰

DALYs for people with TB: Globally, various studies have used Disability Adjusted Life Years (DALYs) to understand the impact and consequences of TB.^{41,42,43,44,45} This measure is often used to understand the burden of disease beyond mortality rates, which does not wholly represent the impact of disease in a population.⁵¹ DALYs for a disease or health condition are the sum of the years of life lost to due to premature mortality (YLLs) and the years lived with a disability (YLDs) due to prevalent cases of the disease or health condition in a population.⁵¹

Worldwide, 58 million DALYs were due to post TB sequelae in the year 2019, of which 12.1% DALYs were due to per incident TB case, 6.3% DALYs were due to the TB episode (short-term), and 5.8% DALYs were because of the long-term effects of TB.⁵⁰ The burden was highest in younger individuals and in countries with high incidence of TB.⁵⁰ In a study done in a county in Texas, USA in 177 culture confirmed cases (with pulmonary and extrapulmonary TB), authors found that a total of 1,189 DALYs were lost to TB. Of the DALYs 23% were mortality rates, 2% was lost to acute disease whereas a staggering 75% was lost to chronic disability. The study acknowledged the infrequent paediatric cases in the county; hence the effect of age was not considered in the final

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data analysis.⁵² In Korea, the burden of MDR-TB and Drug-Sensitive TB was found to decrease from 2014-2017. However, the trend showed a continued high burden of years lost to TB in DALYs.⁵³ In Malawi in Africa, between 2016-17, DALYs for persons >15 years of age were found to be greater after three years post-treatment with high loss for persons with co-infection of HIV.⁵⁴

Health-Related Quality of Life and TB: Health-related quality of life (HRQoL) is used to understand the morbidity burden of chronic diseases such as diabetes, stroke, cancer, and heart disease.⁴⁶ Today this measure has been extended to understand post-TB QoL.⁷ HRQoL is a multidimensional self-perceived measure of a person's health status and the mental and physical functioning related to the perceived health status, which goes beyond the medical/physical manifestations and the impact of a disease. It provides information on the QoL related to the health status of an individual.^{55,47} In a systematic review done to assess health status related to TB, authors found that although various studies recognised the impact of TB on health status, they failed to acknowledge the HRQoL of TB sequelae, readily assuming the return to normal health status post-TB treatment. Some of the common reasons cited for poor health status were physical and psychological impact, stigma and social isolation, greater costs for accessing care, medication costs considering loss of employment and long-term impairment that furthered the stigma cascade. This was worse in specific groups including children and adolescents,¹⁶ those with HIV co-infections, and latent TB.⁷ A study conducted in Iran between 2009-11 on functional QoL measures found that physical functioning and energy levels were lowest among other measures on the SF-36 questionnaire despite completion of treatment.⁴⁸ HRQoL measured using the WHOQoL-BREF scale in a primary health care facility among 81 patients in Indonesia showed that most patients were dissatisfied with their QoL, particularly related to their physical health. Additionally, more than half the study sample perceived their general health status as 'bad' or 'very bad' indicating poor QoL among those with TB.⁴⁹ Thus, the impact of TB on the quality of life is acknowledged but understudied in India and across the world.

Persons with Disability and Tuberculosis – An Intersectionality

Over a billion people i.e., 15% of the global population suffer from some form of disability. Disability by the WHO is defined beyond medical impairments and relates to interactions of a person's health condition with the social context and includes factors such as inaccessibility to social services and restriction in social participation due to environmental barriers.⁵⁰ In India, according to the Census 2011³⁵, 2.21% or 26.8 million people have a disability. However, it is projected that these numbers will increase with the rise in the ageing population and the burden of non-communicable diseases.⁵¹

A report based on the intersectionality of HIV/AIDS and disability, developed by UNAIDS, called for a need for a cross-sector, multisectoral framework for action using a three-track approach i.e. mainstreaming persons with disabilities through equal participation, increasing funding, and development of disability-inclusive policies and programmes to enhance QoL of such persons.⁴⁸ Other research has highlighted the intersectionality between HIV/AIDS and persons with disabilities and the need for special attention and immediate action to this issue.^{47,52}

The COVID-19 pandemic changed the world's 'normal'. People with lower immunity were at a higher risk of mortality. The Indian Institute of Public Health, Hyderabad studied 403 persons with disabilities in India during the COVID-19 pandemic.⁵³ The findings revealed that 42.5% did not have access to routine medical care and 45% did not have access to emergency medical care. Another study jointly undertaken by Vidhi Centre for Legal Policy and the National Centre for Promotion of Employment for Persons with Disabilities found that out of the 146 people with disabilities interviewed, 87.7% of the respondents were unable to access door-to-door vaccination services.⁵⁴ Shortage of medical equipment and the nearly 50% drop in blood count at blood banks severely impacted many persons with disabilities including those with thalassemia and haemophilia.⁵⁵ Although the government introduced inclusive guidelines to protect persons with disabilities during the COVID-19 pandemic, this did not translate into uniform implementation at the state-level. As states were left with discretionary powers rather than a mandate, questions remain on how the guidelines unfolded in practice.⁵⁶

HIV/AIDS and COVID-19 provide a glimpse into the health challenges of and the difficulties faced around accessing healthcare for persons with disabilities. However, in the case of TB, there is far less information on the short- and long-term effects of TB on persons with disabilities, both globally and in India. Furthermore, there is little-to-no information on the experiences of persons with disabilities along the TB care cascade.

Reaching vulnerable populations: Evidence suggests that target-driven health programmes carry with them the inherent danger of unintentionally excluding vulnerable populations. In a study in New Delhi between 1996-98, researchers found that in the absence of adequate support to frontline health workers and patients, short-course treatment under the then RNTCP was provided if "the health worker was confident that the patient would comply and/or be easy to trace in the community in the event of 'default'. Other patients, largely those who were in absolute poverty, socially marginalised, itinerant labourers, poorly integrated in the city, were put on standard tuberculosis (TB) treatment as per the previous National TB Programme. The programme was evidently excluding the most vulnerable from the best available care⁵⁷." However, today the National TB Elimination Programme⁷² has come a long way in trying to ensure wider reach and more inclusive care by emphasising priority populations.

People with disabilities are one such vulnerable population that report worse health outcomes than those without disabilities.⁵⁸ A study done in Malawi reported that persons with disabilities are at a higher risk of TB due to poor access to information and healthcare services.⁵⁹ In India, persons with disabilities rarely enter the public healthcare system. Community attitudes especially towards mental illness also constrain persons with disabilities from accessing health care. Factors such as physical accessibility of health care institutions further hampers persons with disabilities from accessing health care. This is further compounded due to the poor health outcomes of persons with disabilities who require constant medical attention.⁶⁰ The World Health Organization reported in 2018 that 53% of people with disabilities are unable to meet medical costs as opposed to 32% of those without disability.⁶¹

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In India, one of the main reasons cited in the literature for continued inaccessibility is the lack of collaboration between the Ministry of Health and Family Welfare and the Ministry for Social Justice and Empowerment.⁶² Inclusive measures are urged for all national health programmes (including the TB programme), which have a significant number of persons with disabilities as care-seekers. Generation of a quality database is crucial to tracking vulnerable populations such as persons with disabilities who otherwise fall between the cracks of the healthcare system.⁶⁷ The Ministry of Health and Family Welfare has released Accessibility Standards in 2022 to ensure physical accessibility of healthcare institutions and sensitisation on how to interact with service users who have disabilities.⁶³ Indian healthcare providers need to be trained and monitored to ensure better implementation of these standards.

Impact of anti-TB drugs: The use of anti-TB drugs can lead to drug toxicity, particularly in those with MDR-TB, which increases the incidence of disability in those affected. This creates a cycle of vulnerability that is an unexpected outcome of treatment. Although the healthcare system has significantly improved, there is a lack of systemic mechanisms to address drug toxicity. First line-drugs such as isoniazid, rifampicin, pyrazinamide, ethambutol and streptomycin were analysed and found to be extremely toxic sometimes leading to even mortality as a side effect.⁶⁴ Progressive public health measures are required to actively mitigate side-effects of drugs and reduce the burden of disabilities among those with TB.

Long-term Care for TB: Long-term care is crucial for people with TB. The programme mandates follow-ups for two years at intervals of six months. These follow ups are prescribed in the guidelines to assess reinfections. However, often because of severe lung damage (in case of pulmonary TB), TB survivors experience reduced HRQoL (as discussed in other sections of this report). This underlines the need for systematic follow up by the healthcare system. A study has shown that the mortality rate of TB survivors is 2.92 times higher than those without TB.⁶⁵ Another study examined the post TB sequelae of patients in a high burden country. Of the 117 patients whose chest X-ray was examined, only 11 of them showed complete resolution. 106 of those patients had parenchymal and pleural sequelae. The researchers of this study explained that this meant very few of the patients completely recovered from TB and their lungs were still affected by TB and could not function at full capacity. The persistence of the respiratory symptoms would have adverse psychosocial and financial repercussions.⁶⁶ Holistic follow ups become crucial to ensure that TB survivors receive the constant care they need to mitigate the multidimensional sequelae of the disease.

Furthermore, the need for follow-up after the person is deemed TB negative is emphasised in the literature. A study in Telangana of people with TB who were cured showed that follow-ups were crucial to improved health incomes in more than 2/3rd of those interviewed and also led to post-treatment survival rates of 92% in index cases (cases that are the first to be documented during an outbreak of TB).⁶⁷

Apart from socio-economic and pulmonary TB follow up, disabilities caused due to TB and TB medications must be taken into account. This means TB survivors may not only require extended medical care but also rehabilitation. A robust system to facilitate the same is required as suggested in the literature. A low-cost high impact solution including rehabilitation and peer-to-peer counselling may serve as solutions for LMICs such as India.⁶⁸ Rehabilitation measures required in healthcare systems include physiotherapy, long-term oxygen therapy, ventilation, educational and psychological counselling and exercise training.⁶⁹

Government schemes for people with TB: One of the major initiatives of the government was the introduction of the Nikshya Poshan Yojana (March 2018) scheme for those affected with TB. The scheme was set up for all those notified and treated to provide additional nutrition support. This support is provided in the form of cash (Rs. 500/month) through a direct benefit transfer or in kind (ration).⁷² Another scheme launched by the Government of India in Sept. 2022 aims to mobilise the community in the elimination of TB by 2025.⁷⁰ The objectives of the Pradhan Mantri TB Mukta Bharat Abhiyaan are to provide additional patient support to improve treatment outcomes of TB patients, augment community involvement in meeting India's commitment to end TB by 2025, and leverage Corporate Social Responsibility (CSR) activities. To achieve the vision, the scheme has incorporated three components: Nikshay Mitra Initiative is to ensure additional diagnostic, nutritional, and vocational support to those on TB treatment; Nikshay Mitra (Donor) are those who can support by adopting health facilities (for individual donors), blocks/urban wards/districts/states for accelerating response against TB to complement government efforts; Nikshay Digital Portal will provide a platform for community support for persons with TB. People with disabilities can be prioritised within both these schemes.

Currently there are no links or access to any of the disability-related schemes, data as per the Unique Disability Identity (UDID), specific state-related benefits for persons with disabilities⁷¹ or disability pensions (Indira Gandhi National Pension Schemes – decentralised)⁷² for those with acquired impairments due to TB. This leaves those with TB with little choice for long-term care.

Other schemes for persons with disabilities are mentioned in Annexure 1.

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66. Gohar A M, Syed M Z, Shahzad T, Yaseen A, Irfan M. Post tuberculosis sequelae in patients treated for tuberculosis: An observational study at a tertiary care center of a high TB burden country. *European Respiratory Journal*. 2018 Sep 15; 52(62):PA2745. doi: 10.4081/monaldi.2021.1814. PubMed PMID: 34340298.

67. Mathur N, Chatla C, Syed S, Patel Y, Pattnaik S, Mathai D, et al. Prospective 1-year follow-up study of all cured, new sputum smear positive tuberculosis patients under the Revised National Tuberculosis Control Program in Hyderabad, Telangana State, India. *Lung India*. 2019 Nov-Dec;36(6):519-524. doi: 10.4103/lungindia.lungindia_143_19. PubMed PMID: 31670300. PubMed Central PMCID: PMC6852225.

68. Kumar BA. Rehabilitation of treated TB patients: Social, psychological and economic aspects. *Int J Mycobacteriol*. 2016 Dec;5 Suppl 1:S129-S130. doi: 10.1016/j.ijmyco.2016.11.021. PubMed PMID: 28043504.

69. Visca D, Tiberi S, Centis R, D'Ambrosio L, Pontali E, Mariani AW, et al. Post-tuberculosis (TB) treatment: The role of surgery and rehabilitation. *Applied Sciences* [Internet]. 2020 Apr 15 [cited 2022 Sep 3];10(8):2734. Available from: <https://www.mdpi.com/2076-3417/10/8/2734>.

70. Ministry of Health and Family Welfare. PRADHAN MANTRI TB MUKTA BHARAT ABHIYAAN, Guidance Document - Community Support To TB Patients [Internet]. Ministry of Health and Family Welfare. 2022 [cited 2023 Jan 11]. Available from: https://tbcindia.gov.in/WriteReadData/1583929709Guidance%20Booklet_02-08-2022.pdf.

71. Disability Schemes [Internet]. Unique Disability ID, Department of Empowerment of Persons with Disabilities, Ministry of Social Justice & Empowerment, Government of India. [cited 2022 Aug 16]. Available from: <https://www.swavlambancard.gov.in/schemes/search>.

72. Indira Gandhi National Disability Pension Scheme (IGNDPS). Dhenkanal District : Odisha, India [Internet]. Government of Odisha. [cited 2022 Aug 16]. Available from: <https://dhenkanal.nic.in/service/indira-gandhi-national-disability-pension-schemeigndps/>.

4. Key Findings from Qualitative Research

This section draws on qualitative interviews to describe the state of inclusion of disability in the TB care cascade. Common themes were generated through the accounts of all stakeholders interviewed. The section is organised to provide a sequential account of the challenges (as seen by the various stakeholders) along the care cascade – from the point of being diagnosed with TB until they are cured of the disease. This section also shows that the story does not end there. For many, TB means living with the long-term sequelae of disease. The section also includes recommendations provided by technical and community experts as well as researchers on improving the visibility and inclusiveness of care for disability.

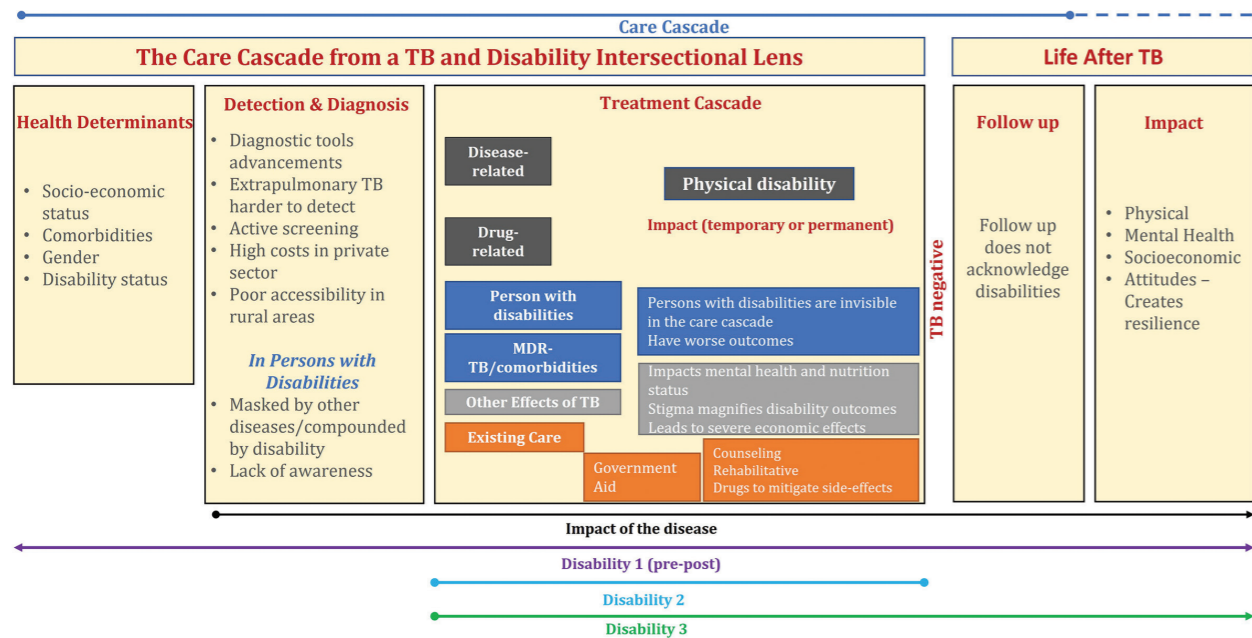


Diagram 2: Diagrammatic representation of the summary of findings of the intersection of TB and disability in the care cascade.

The above diagram is a representation of the themes uncovered from the different interviews and is organised in chronological order of the care cascade. Demographic factors determine the likelihood of a person being affected by TB and ultimately affecting their health outcome including acquiring a disability - health determinants. Detection and diagnosis form the basis of the TB programme but has multiple challenges particularly when considering PwD and other vulnerable populations. In the treatment cascade, disability can be acquired due to the nature of disease or the side-effects of drugs leading to either temporary and permanent disabilities. TB has a multipronged impact on the person's mental health, socio-economic status, and nutritional status. After people are declared TB free/negative, follow up programmes allow for the monitoring of reinfection rates. However, follow ups do not account for monitoring the disability outcomes in the patients. Life after TB is marred with having to live with a disability, lack of occupational support and mental health issues.

This rapid assessment has revealed that disability in the TB context is primarily of three types:

Disability 1: where an individual enters the TB care cascade with the disability and leaves with the same disability or in addition has acquired a new disability along the way.

Disability 2: disability acquired during treatment that resolves when drugs are discontinued or the treatment regimen is changed.

Disability 3: disability acquired during treatment but persists as a lifelong disability (permanent).

4.1 The Care Cascade from a TB and Disability Intersectional Lens

Pre-Diagnosis - Health Determinants

Several factors affect vulnerability and susceptibility to TB. This rapid assessment has confirmed that the more disadvantaged or vulnerable a person is at the start of the treatment, the higher the probability that they will be worse off at the end of the treatment period. In case of acquiring a disability due to TB, the intersectional vulnerabilities play a critical role in determining the quality of life of the person.

Socio-economic status: TB disproportionately affects those coming from lower socio-economic backgrounds.⁷³ Studies show that the multidimensionally poor population is 1.82 times more likely to contract TB than the rest.⁷³ However, this by no means indicates the non-susceptibility of the middle- and high-income population to TB.

"It is not a poor man's disease anymore. It has a component of nutrition, but the incidence is high among other classes as well. If a person with high economic status contracts it and completes treatment, it is not too hard on them. The impact of the disease is likely to be higher on those who engage in more physical labour."

- Clinician and Programme Implementer

A Chest Physician drew the link between socio-economic status and the susceptibility to acquiring a TB-related disability.

"Respiratory disability is one of the most severe form of disabilities. It is a function of the nutrition of people before they contracted the disease as well as the duration of the illness before the diagnosis was made and the treatment was initiated. So it's more common among people who are poorer and further away from the health systems. Hence, disability due to pulmonary tuberculosis is an inequity driven phenomenon."

Comorbidities: Comorbidities at the time of acquiring TB may directly influence disability outcomes of the disease. India's NSP has identified HIV, diabetes, undernourishment, smoking and alcohol use as some key risk factors that contribute to the incidence of TB.²²

For VK, a 49-year-old man from TN, working in a tobacco smoke-filled environment had its bearings on the treatment.

"My shop is near a cigarette shop, and the smoke entered my lungs. It was hard to detect the problem as I don't have any bad habits. I was advised to take medication and rest at home for four months which I did. I am back in my shop, but the cigarette smell makes me nauseated and uncomfortable."

Four PwTB interviewed had diabetes prior to the onset of TB. One of them lost their eyesight due to an increase in blood pressure during TB treatment.

73. Pathak D, Vasishta G, Mohanty SK. Association of Multidimensional Poverty and tuberculosis in India. BMC Public Health. 2021 Nov 11;21(1):2065. doi: 10.1186/s12889-021-12149-x. PubMed PMID: 34763696. PubMed Central PMCID: PMC8582202.

"If a person has TB and diabetes, we have to treat both and not just TB to get them cured."

- WHO Consultant

Another clinician noted that those with prevalent comorbidities like HIV, or those on dialysis, are also evaluated for TB. This has proved beneficial from a patient perspective. TV, who is undergoing dialysis, suffered from shortness of breath which led to a diagnosis of shrunken kidneys. Shortness of breath is also a symptom of TB which he later contracted. When two comorbidities have similar symptoms, it is likely that one is overlooked.

Gender: Multi-dimensional studies on the gendered aspects of TB show that men are nearly twice as susceptible to the disease as women due to factors such as increased exposure to community, high-risk work environments, and increased engagement in high-risk behaviours such as drinking and smoking.⁷⁴

"Women generally come later into the care cascade than men. Women are brought late, and nutrition is lacking. So, there is a gender problem."

- Clinician and TB Expert

This observation is corroborated by current literature.⁷⁵ A study among people with TB in Mumbai found that significantly more women than men experienced diagnostic delays.⁷⁶ In India, marriage status tends to be a key variable differentiating experiences of healthcare seeking: unmarried women delay healthcare seeking on account of social stigma, while married women report being too consumed by domestic responsibilities, lack of financial resources, and lack of mobility.⁷⁷ Delayed diagnosis can increase the likelihood of developing MDR-TB or TB-related disabilities in women. The NTEP has adopted a National Framework for a Gender-responsive approach to TB. Further research is needed to understand the long-term impact of disease through a gendered lens.

Disability Status: While none of the experts we interviewed went into detail on the influence of disability status on susceptibility to the disease, there was a general acknowledgement that existing disabilities resulted in a higher predisposition to TB.

"People with vulnerable nutritional status, and mental or physical disabilities, have a higher predisposition to start with. Once they get TB, their ability to access treatment is affected because of their disability. And since TB treatment is long drawn, their agency to continue treatment is also affected. For instance, if they're expected to reach out to hospitals every month for continuing treatment, their disability is a detriment. The outcomes of treatment in PwD are much poorer, and this is made worse by the unresponsive health systems. So, I think a person with disability will have a poorer outcome than a person without disability, for the same weights and the same social groups they belong to."

- Chest Physician and Clinician

A disability expert pointed towards the likelihood of delays in diagnosis of TB in people with disabilities due to their disabilities masking symptoms. One of the PwD interviewed, SJ, faced this difficulty. He had experienced pain in his hands for a long time, but bone TB was diagnosed much later.

Several of the experts did not seem to have considered the intersection between disability and TB beforehand. While there is no conclusive evidence that points towards a higher susceptibility of TB in persons with disability, the correlation between undernutrition and TB,²² and undernutrition and disability,⁷⁸ have been widely recognised. Undernutrition can be a cause as well as a consequence of both TB and disability. Further research on this will help establish the relationship between TB and disability that remains primarily observational as yet. This will also benefit an enhanced understanding of the complex relationship between TB, disability and the other health determinants mentioned in this section, such as gender and comorbidities.

Detection and Diagnosis

Detection and diagnosis form the cornerstone for control and elimination of a disease. Most TB experts and policymakers discussed the advances in testing methods and availability of better diagnostic tools under the TB programme and increased efforts towards active case finding⁷⁹ seen through mobile door-to-door programmes.

Case notification rates are critical routine surveillance indicators that are collected by governments to better plan and implement TB programmes.⁸⁰ India mandates case notifications from public and private sectors, through the Nikshay portal which was acknowledged as a game-changer by experts particularly in the context of the private sector.

Experts also discussed the advances in baseline drug-resistance testing. With India among the four countries contributing to 60% of the global burden of MDR-TB cases⁸¹, the government has taken steps to identify resistance early through universal drug susceptibility testing.

However, there are geographical disparities in availability of testing for TB. Over 65% of India still lives in rural areas,⁸² where access to healthcare is low. This is especially true for access to X-rays. A person with TB described how she had to spend over Rs. 50,000 on treatment as she had to travel to the closest urban centre for access to scanning centres. Experts also concurred that extrapulmonary TB is harder to diagnose. A programme implementer pointed out that there is no extra effort made to screen for extrapulmonary TB due to its nature i.e., being non-communicable. As a result, this type of TB gets detected by chance, after considerable delays.

People with disabilities and diagnosis of TB: All disability experts directed attention towards the invisibility of disabled persons in the overall health system, and therefore, in the TB care cascade.

74. Horton KC, MacPherson P, Houben RM, White RG, Corbett EL. Sex differences in tuberculosis burden and notifications in low- and middle-income countries: A systematic review and meta-analysis. *PLoS Med*. 2016 Sep 6;13(9):e1002119. doi: 10.1371/journal.pmed.1002119. PubMed PMID: 27598345. PubMed Central PMCID: PMC5012571.; Humayun M, Chirenda J, Ye W, Mukeredzi I, Mujuru HA, Yang Z. Effect of gender on clinical presentation of tuberculosis (TB) and age-specific risk of TB, and TB-human immunodeficiency virus coinfection. *Open Forum Infectious Diseases*. 2022 Oct 5;9(10):ofac512. doi: 10.1093/ofid/ofac512. PubMed PMID: 36324321. PubMed Central PMCID: PMC9620549.

75. Karim F, Islam MA, Chowdhury A, Johansson E, Diwan VK. Gender differences in delays in diagnosis and treatment of tuberculosis. *Health Policy and Planning*. 2007 Sep;22(5):329-34. doi: 10.1093/heapol/czm026. PubMed PMID: 17698889.

76. Mistry N, Rangan S, Dholakia Y, Lobo E, Shah S, Patil A. Durations and delays in care seeking, diagnosis and treatment initiation in uncomplicated pulmonary tuberculosis patients in Mumbai, India. *PLoS One*. 2016 Aug 3;11(8):e0160796. doi: 10.1371/journal.pone.0160796. PubMed PMID: 27486896. PubMed Central PMCID: PMC4972312.

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79. Burugina Nagaraja S, Thekkur P, Satyanarayana S, Tharyan P, Sagili KD, Tonsing J, et al. Active case finding for tuberculosis in India: A syntheses of activities and outcomes reported by the National Tuberculosis Elimination Programme. *Tropical Medicine and Infectious Disease*. 2021 Nov 30;6(4):206. doi: 10.3390/tropicalmed6040206. PubMed PMID: 34941662. PubMed Central PMCID: PMC8705069.

80. Tuberculosis notification rate [Internet]. World Health Organization; [cited 2022 Oct 16]. Available from: <https://rho.emro.who.int/Metadata/tuberculosis-notification-rate>.

81. Ou Z-J, Yu D-F, Liang Y-H, He W-Q, Li Y-Z, Meng Y-X, et al. Trends in burden of multidrug-resistant tuberculosis in countries, regions, and worldwide from 1990 to 2017: Results from the global burden of disease study. *Infectious Diseases of Poverty*. 2021 Mar 6;10(1):24. doi: 10.1186/s40249-021-00803-w. PubMed PMID: 33676581. PubMed Central PMCID: PMC7936417.

82. Rural population (% of total population) - India [Internet]. The World Bank. 2018 [cited 2022 Oct 16]. Available from: <https://data.worldbank.org/indicator/SP.RUR.TOTL.ZS?locations=IN>.

"The healthcare system is first of all not physically accessible. Second, the process is not accessible. With all these kinds of special care, I do not think the patients know where to go. All that they know is that they would like to go to the primary centre. How many primary health care centres are disabled-friendly? How much of the procedure of the healthcare system is disabled-friendly? Is a couch accessible for a disabled girl? For a physically disabled girl, if the couch is very high, or is placed at a taller level, how will she be able to access it? But then, if the doctor wants to do a physical examination, won't she (the disabled girl) feel bad about it? Won't it prevent her from seeking healthcare?"

- Medical Professor

"There are challenges because they are dependent. They can't just walk in because of their disability. Health-seeking behaviour is different. Some behaviour change education is to be given to the general population to bring PwD to treatment. We have to increase field-level activities to not miss this population with disabilities."

- TB Expert

For SJ, a 21-year-old PwD from New Delhi, the effect of the disease was exacerbated by delays in diagnosis and inadequate care during the course of the treatment.

"My hand got hurt a long time ago. Maybe if I had paid attention or noticed earlier, I would have had better results from the treatment. The people from the children's home did not care, but when I got considerable inflammation in my hand, I requested the Child Welfare Committee Chairman. He wrote and gave a letter addressed to the Chief Medical Officers at AIIMS Delhi. When my hands were inspected, it was found that I have bone TB. It was diagnosed in 2015-2016, but the Child Welfare Committee home got changed a couple of times. I was shifted to different homes, so because of that my treatment was being interrupted every time."

Experts pointed out that higher mortality rates, the masking of TB by existing disabilities and ambiguities in diagnosis as other difficulties in diagnosing and treating people with disabilities for TB.

From the perspective of those affected, getting a diagnosis of MDR-TB may have more severe delays. Seven PwTB and one PwD we interviewed had drug-resistant TB. Several people with MDR-TB recounted having undergone months of treatment for drug-sensitive TB before they were diagnosed with drug-resistance TB, and given the correct treatment. For RK, a 29-year-old man from Bihar, it took multiple consultations over a period of nine months to get an DR-TB diagnosis.

"I started six months of treatment and I was not getting better, then I took nine months of medication and I was still not getting better. Then I told the doctor, I am not getting better, there must be some process beyond this, but no change in treatment so I thought I would consult another hospital. I went to another district; they told me I had DRTB. I finished my treatment in 2017. My hand and leg were affected. People told me it was eczema, I thought it would get better now that the medicine is over but slowly it is spreading. It has been 5 years now."

Legal perspective: The Rights of Persons with Disabilities Act, 2016 does not recognise heart and lung disabilities, thus denying those with such disabilities the rights and entitlements vested under the Act. Several experts expressed their dissatisfaction with the fact that the narratives around disability are hyperfocused on visible or conventional disabilities.

"Our entire disability certification system is very physical disability centred. Physical as in, bone or skin. They don't look at lung or heart disabilities. A change in that paradigm should happen."

- Chest Physician

Recommendations:

- Reduce delays in diagnosis, including by improving health seeking behaviour, to prevent sequelae⁸³
- Strengthen sputum collection and transportation/use of mobile diagnostic units to reduce physical access challenges
- Sensitise and train healthcare workers to fast-track diagnosis among people with disabilities
- Ensure active case-finding among institutions and centres for people with disabilities
- Consider amending the Rights of Persons with Disabilities Act, 2016 to include heart and lung disabilities/functional disabilities, either directly or via a separate enactment such as the HIV and AIDS Act

Treatment

The TB disease by itself as well as the drugs administered in the treatment of TB can impact a person with TB in ways that result in disability in the short or long term. Several experts stated that the duration of the disability, i.e., whether it is temporary or permanent, would be dependent on factors such as the type of TB contracted, existing comorbidities, and any delay in diagnosis. Experts were unanimous that drug-resistant TB could result in more severe disabilities, both physical and mental.

Disability as an Effect of TB: Interviews with people with TB indicated that disability was, in several instances, a direct outcome of TB. 11 out of the 13 PwTB had acquired either a temporary or permanent disability after contracting the disease. A person with a pre-existing disability found a greater severity of disability post TB.

Three PwTB interviewed were initially misdiagnosed, and eight PwTB had delayed diagnosis. NV, a health advocate and TB survivor, narrated her experience

83. World Health Organization. Systematic screening for active tuberculosis: an operational guide [Internet]. World Health Organisation: Geneva. 2015 [cited 2023 Jan 10]. Available from: https://apps.who.int/iris/bitstream/handle/10665/181164/9789241549172_eng.pdf.

"The diagnosis back then was delayed by a few months. But again, it was only two or three months for me. I know people whose diagnoses were delayed for much longer. I remember I started showing the symptoms in August 2007. And the actual diagnosis only happened around November or something, and it was in the intestine."

There was consensus among the experts that lung disability was the most common and also the most severe. It is exacerbated when the diagnosis is delayed, often resulting in a lifelong respiratory cripple.

"TB is a consuming disease. It damages the body as well as the organs within it. 70% of the patients' lungs are affected. This is the organ through which oxygen enters the body and if the lungs are destroyed even partially, they would cause respiratory cripples. If the destruction of lungs is too much, it does not allow a person to return to work, so it becomes a serious disability."

- Chest Physician

Other impacts of the disease also include empyema and pulmonary fibrosis. A common effect of pulmonary TB was shortness of breath, which restricts the affected person from returning to work.

"If you look at it in one way, even coughing for six months is a disability because cough can be the most stigmatising symptom. A proper definition of what you would consider disability is important. Cough, quality of life – how many people even assess that pre-treatment and post-treatment? Like having the ability to climb up the stairs, doing the domestic chores, especially for women."

- TB Expert

Some experts highlighted the long-term impact of extra-pulmonary TB, like TB of the spine or of the bone, which result in disabilities. SJ, a person with TB, can only move his hand 40-50% of the time. A rehabilitation professional observed that most of the TB-related disabilities he had encountered were spine-related. In severe cases of spinal TB, people may end up with a complete lower body paralysis.

Experts also described the nature of the impact of TB on the nervous system. Tingling, numbing and burning sensations in the legs were common manifestations of peripheral neuropathy resulting from TB. When TB affects the brain, it can result in double vision and/or seizures. Two of the people with TB we spoke to suffered from brain TB. Both of them had fallen into a coma at some point during the course of the disease. CB, a 27-year-old woman from Odisha, who then became paralysed, recounts her experience.

"I was in a coma for 45 days, I had total memory loss, I forgot everything. I was pregnant at that time, so they aborted the child. The doctor gave me medicine for 18 months, and I became paralyzed on one side, my leg and hand."

AMT, a 42-year-old woman from Jharkhand who had contracted TB as a child, poignantly described her experience.

"My parents were told that as I had brain TB, it might affect a part of my body. My father checked my legs and hands everyday but they never suspected it would affect my eyes. I lost my vision, and I childishly asked why the doctor had a snake around his throat, that's when the doctor had a feeling that something might be wrong with my eyes. It was too late though, just like no matter how much water you put on a dry tree, it does not become green again, it was like that for me."

Drug-Induced Disability: Experts were of the opinion that drug-induced side effects of TB were usually resolvable, and did not lead to long-term disabilities. They agreed that drug induced morbidities are not serious unless it is ignored and not treated, and usually either partially or completely reversible once the drugs are stopped. However, side effects of second line-drugs can be more severe.

"The side effects of drug-sensitive TB are very minimal, mostly nausea and vomiting. These are manageable at the primary and secondary health centres. Very rarely there could be severe side effects like jaundice or blurring of eyes or peripheral neuropathy. Then they are referred to secondary or tertiary care."

- TB Expert

However, there are potential long-term effects.

"The common TB drugs can result in jaundice and liver disease, and if not looked after well, it can result in death. Usually it is reversible. Sometimes, skin rashes can happen, which can be treated and is not disabling. Drugs like Ethambutol can cause colour vision problems or even blindness. It's not very common, maybe just 2-4%. It usually resolves, but if it doesn't, it can result in permanent damages."

- Chest Physician

Some of the other common side effects of the drugs as mentioned by the experts were vision loss, hearing loss, hepatic diseases, peripheral neuropathy and arthritis. Mental health issues, including depression, is also a common side effect of second-line drugs. Three people with TB we interviewed were consulting psychiatrists. Two people found the effects of the drugs to be harrowing. AK, a 28-year-old man from Bihar, recounted.

"He (the doctor) prescribed medicines for MDR-TB. When I started eating the medicines, I had a lot of side effects, a lot, meaning, I could not even sleep, I absolutely couldn't get sleep, my heart beat was very fast, I was thinking that I was going to die."

MO, a 30-year-old woman from Nagaland had a similar experience.

"Maybe it was the side effects of the medicine, but I lost every hope in living. I thought I wouldn't live anymore and even if I did, that my life wouldn't be normal anymore. I was depressed and had suicidal thoughts. I had a lot of problems that I cannot even speak about. I wanted to die by suicide because I could not even get up from my bed."

Second-line drugs resulted in ototoxicity for a TB survivor who is now an active health advocate. One person reported an addiction to the pills, and another reported paranoia on stopping the medicine. Technical experts pointed out that not much has been done to assess the physical and mental health sequelae, and that though short-term side effects have been studied, the same is not true of the long-term effects of TB drugs.

In this context, programmatic steps are being taken to bring about systemic changes to the drug delivery system. Pharmaceutical strides are being made in providing better quality drugs for the treatment of TB. Introduction of better drugs, more streamlined drug delivery systems, intensification of drug sales, flexibility given to Medical Officers to determine regimens and surveillance were some of the systemic successes cited. Experts asserted that drug regimens were well accepted by those on treatment, shorter regimens that are more comfortable have been introduced for DR-TB and treatment is monitored well to ensure completion of the regimen. However, a more decentralised, systematic and person-centred pharmacovigilance approach is required to further minimise both short- and long-term impact of the drugs.

Experts also drew attention to the need for better treatment literacy and greater empowerment of those on treatment, which will help in earlier identification of side-effects and better management of the disease.

"Awareness is lacking among people with TB. Because of the power imbalance, they don't demand the services they require. They should be empowered so that they can demand these services."

- TB Project Implementer

Eight of the participants who contracted TB and had severe drug reactions that ended up in some form of disability highlighted the lack of information provided by doctors regarding potential side-effects of the drugs.

"I suffered this hearing loss because of kanamycin injections. We are administered these intramuscular injections for 100 days or something and a week after the injections were stopped is when I actually lost my hearing. We need to have better drugs than just Kanamycin injections. The TB programme in India has asked the states to phase out Kanamycin and scale up new drugs. That's good, but we need proper implementation on the ground. It is also important to inform people beforehand that Kanamycin may have potential side effects such as hearing loss. The caregivers should also be asked to watch out for signs or symptoms of things such as hearing loss."

- TB survivor and advocate

Recommendations:

- Include Disability as an individual-level variable on Nikshay. All people with TB registered on Nikshay are given a TB Identity Card and a TB Treatment Card under the NTEP. Inclusion of a column on the pre-existence of a disability and the type of disability will help track TB-related sequelae, thus making it easier to monitor and address specific problems faced by this population. This will also facilitate the tracking of people with disabilities who are diagnosed with TB and enter the care cascade. This one action can greatly expand the availability of data and information on TB and disability including treatment outcomes, mortality, comorbidities etc.
- Develop and establish a robust surveillance system for identification of adverse drug reactions and side-effects, as part of routine treatment support.
- Develop and disseminate clear guidelines on how TB-related complications are to be addressed and streamline referral systems for management of complications within public and private healthcare facilities. These referrals include but are not limited to TB-related surgeries, eye-care, rehabilitation and prosthetics and orthotic facilities, and additional nutritional support.
- Expand and make widely available combination of person-centred care with peer support and use of technology/artificial intelligence to monitor and minimise impact of side-effects for people on treatment, to minimise drug-reactions.
- Ensure treatment literacy for all people on treatment and their families, particularly on potential side effects. Several people with TB interviewed mentioned that they were not aware of the potential side effects of the treatment, and would have been more vigilant and sought medical care sooner if they had known. The potential side effects of the drugs must be communicated effectively and sensitively to people with TB so that they are aware of its consequences, but are not deterred from treatment completion out of fear.

Persons with Disabilities and the TB Care Cascade

There was consensus among experts that at present, the TB programme does not recognise the needs of people with disability. Once they are diagnosed with TB, they are inevitably treated the same way as persons without disability, without any special considerations. Most clinicians acknowledge that the effects of the disease are magnified when the person has a pre-existing disability.

"For such people (PwD), the diagnosis of TB is even further delayed because it is harder for them to access care. I can think of at least two to three persons who had a disability and then got TB, and most of them have an extensive disease when they're diagnosed because with disability, everything is more difficult. We don't know how many people with disabilities actually never get to us and simply die of the disease. Even for people with no pre-existing conditions, the death rates are so high, so for PwD, I presume it must be much higher."

- Chest Physician

The understanding of the experts was mirrored by the experience of those directly affected. SJ was one such person.

"If a visually impaired person gets TB, they need special attention because a normal person can take care of themselves but those who are like me, might not be able to take care of themselves. I have been unable to take the medicines a few times which might have led to my MDR diagnosis. So, it would be nice if the government looked into the disabled sector and thought more about what we need."

- Person on treatment for TB

The lack of proper documentation for many people with disabilities is another obstacle. A disability expert pointed out the difficulties that migrant workers with disabilities face in getting a Unique Disability ID (UDID) Card. A person with disability from Telangana who was diagnosed with TB in Delhi shared their difficulty in accessing services even with a UDID card. If the UDID card is issued in a certain state, the person can avail the benefits only in the state where it was issued. Hence, PwD living in different states are often deprived of the benefits they are entitled to under the various schemes.

Recommendations:

- Mainstream disability into healthcare programmes. Disability is a cross cutting issue that needs to be mainstreamed into public health programmes. The systems and policies for the care of persons with disabilities or for treating diseases that cause disability have to be mainstreamed i.e., policies need to be more inclusive. This can only come with a structural change at all levels.
- Incorporate a focus on disability into all aspects of the TB response, including in the development of new tools, policies and strategies and in their implementation.
- Prioritise person-centred care for people with disabilities diagnosed with TB. The lived experience of every person with TB is different. Even in our small interview pool of 18, no two persons had the same experience. Hence, the care they require also varies. Making the care cascade person-centred rather than disease- or system-centred will help target individual needs, thus resulting in better outcomes. This includes home delivery of drugs and state-funded transportation to the treatment centres.
- Ensure Micro-planning for people with disabilities. Experts have unequivocally stated that the effects of TB are doubled or tripled for PwD. Micro-planning for PwD who contract TB will help in addressing the special ways in which the disease affects them. The Ministry of Health and Family Welfare and the Ministry of Tribal Affairs has jointly brought out a Tribal TB Initiative to improve the cascade of care for tribal populations in India. A similar joint initiative by the Health Ministry and the Ministry for Social Justice and Empowerment for disabled persons will go a long way in addressing the specific needs of this population.
- Address disability-related data gaps. As previously mentioned, ensure the inclusion of disability as a variable in Nikshay, both at the time of diagnosis and during post-treatment follow-up.

- Engage communities and civil society in providing effective care and support to people with disabilities. Building local synergies between the TB programme and disability groups can be a first step; local civil society organisations working on disability can be invited to become members of TB Forums.
- Make decision-making bodies more inclusive. The absence of specialised treatment for people with disabilities has been linked to the lack of acknowledgement of disability as a consideration in designing public health systems. Measures must be taken to bring intersectional conversations on public health and disability to the forefront, including enabling the healthcare system to attend to the needs of PwD. Active screening and contact tracing among PwD will help bring more PwD into the system. These considerations are often left out of the mainstream healthcare narrative due to the absence of persons with disability in decision-making bodies. Having people with lived experiences of disability in the core decision-making bodies will ensure that the concerns of PwD are taken into account.
- Undertake active outreach to people with disabilities. A major problem identified by the experts was the lack of visibility of persons with disabilities in the healthcare system due to reasons such as difficulty in accessibility and reluctance to approach the system. Empowering PwD through education and awareness is essential to improve their trust in the public health system.
- Make health centres more accessible. PwD are deterred from accessing hospitals and other healthcare centres since most of them are not accessible to disabled persons. Measures like installing ramps, at least at district-level facilities to begin with, having medical/paramedical staff who can interpret sign language etc. will make the healthcare system more inclusive.

Other Health and socio-economic dimensions of TB and Disability

"You just have to visit ethnographic studies of 10 people with TB in a rural area and you'll realise what it means. Marriages break, children drop out of schools, nutrition levels of the family breaks down, people lose jobs, entire families die by suicide etc."

- Chest Physician

TB is a disease of consumption. Disability can exaggerate the impact of TB on the health and socio-economic dimensions. This section describes other health and socio-economic dimensions that impact TB and Disability.

TB and Mental Health: Mental health is enlisted as a disability by the RPWD 2016. In India, there is growing recognition that mental health needs special attention. This is equally true in the context of TB, where the severity of the disease in itself can cause mental trauma. Projects focusing on mental health have found up to 20% of people with TB reporting mental health issues. Factors such as stigma,⁸⁴ loss of work, feelings of isolation and helplessness, lack of support, losing a will

84. Atre S, Kudale A, Morankar S, Gosoni D, Weiss MG. Gender and community views of stigma and tuberculosis in rural Maharashtra, India. *Global Public Health*. 2011 Jan;6(1):56-71. doi: 10.1080/17441690903334240. PubMed PMID: 21509994.

to live, depression, anxiety⁸⁵ have been well established as common mental health issues faced by people with TB globally.

The majority of people we interviewed reported mental health issues after developing TB disease. TV, a 33-year-old man from Tamil Nadu, found the mental effect of TB to be more challenging than what he experienced physically. Others also reported having lost the will to live. It appears that mental health issues are more severe among those with MDR-TB.

"I really don't have evidence on this, but only anecdotes. Mental health issues is more common among those with MDR, because of the treatment, which results in acute depression and suicidal tendencies. I don't have the data, but collecting that data itself is very important."

- TB Expert

Similar to the physical impact of TB, experts also opined that the mental impact of the disease is enhanced in the case of persons with disabilities. Persons with disabilities have been found to have lower mental health compared to those who do not have a disability.⁸⁶ KU explicitly stated suffering from mental health issues during his treatment due to loneliness, lack of money and job, and social isolation. SJ faced fear of developing another disability, confusion, and lack of support during his diagnosis and treatment. Further research is needed to understand the mental health impact of TB on persons with disabilities.

Stigma: Stigma associated with TB results in ostracisation of not only the person on treatment but also their entire family. Several TB survivors pointed towards isolation and ostracisation as the core reason for their depression.

"My family left me, when I was getting medication. I had a wife but she stayed at her mother's place and my father also left me. When people see me, they go to the side, I am in a lot of distress now."

- TB survivor

Seven out of the 13 PwTB reported facing stigma from the community after being diagnosed with TB. Some others did not reveal their disease to others fearing stigma. A TB survivor, who is now an active health advocate, pointed out that her doctor himself had advised her against telling people that she had TB. PDB contracted TB after the onset of the COVID-19 pandemic. Since most of the population was restricted indoors during this time, they did not face any discrimination. Some others who faced no stigma mentioned having had no interaction with outsiders. However, most people on treatment and survivors narrated several experiences of social exclusion and ostracisation. PL's family were not allowed to draw water from a public well, as the community feared that the entire family was affected by TB.

Some PwTB and PwD expressed relief and gratitude for receiving familial care and support during their treatment, identifying it as an important contributor to the successful completion of their treatment. However, this was not a uniform experience. Experts testified to familial ostracisation as being glaringly visible in the case of married women with TB, especially those who were living with

their husband's family at the time of treatment. For unmarried women, finding a partner becomes difficult if they have the disease. TB is a social disability that deprives people of a normal life.

"When I went for treatment there in my initial stages for MDR, we faced stigma from the villagers and even the medical staff. When the nurses came for a checkup, they didn't check properly because of fear of getting infected."

- TB survivor

In the context of PwD, there is a dual stigma that exists. However, lack of awareness about TB among PwD does not allow them to avail the healthcare services for TB. More research is needed to understand the dual effects of stigma due to TB and disability in those affected.

Economic Effects of TB & TB-related Disabilities: In recent years, the government has made tremendous progress in establishing public private partnership to reduce costs related to TB treatment through provision of free drugs and diagnosis. PL, a 23-year-old woman from Sikkim, narrated her experience with moving from the private sector to a public sector hospital to avail free treatment.

"Initially, when we were taking medicines from the private hospital, we faced problems because my father is a farmer. Medicines were very expensive. We could not get one month's medicines at once. We would get medicines for one week, and after getting money, go for the next week. After shifting to the Government hospital, everything including tests and X-rays were free."

The majority of out-of-pocket expenditure is incurred while searching for a diagnosis, given that people with symptoms first approach the private sector before moving to the public health system.

"In the rural areas of Bihar, people first go to informal providers who give them a higher dose of antibiotics. The symptoms subside for a few weeks and then it relapses. The patient then visits other private practitioners and as a last resort, they get diagnosed. There was a study by the Medical University in Patna which is an urban setup which found that it takes a minimum of three visits to get a diagnosis. In rural areas, it takes 5-6 visits. So the patients end up spending a lot of money. We found that the patients were spending three times their entire household income on treatment. They take loans for treatment, often sell their lands. Men also migrate back to where they were working, so there is a lot of stress."

- TB Programme Implementer

Currently, medical expenses for comorbidities are not covered by the programme, and there is some out-of-pocket expenditure that PwTB need to bear. In addition, the (disability) sequelae of TB, such as hearing and visual impairment come with additional costs for buying assistive devices, which are often expensive. Low proliferation of testing centres in rural areas mean that people have to travel long distances to access appropriate treatment. AMT noted the transport costs due to lack of hospitals in her vicinity. She had to travel till Siliguri as the local hospital near her house did not have an MRI machine.

The economic effects of the disease often transcend the treatment costs. The physical impact of the disease inevitably leaves people debilitated. As a result, getting back to work becomes

85. Naidoo P, Mwaba K. Helplessness, depression, and social support among people being treated for tuberculosis in South Africa. *Social Behavior and Personality: an international journal* [Internet]. 2010 Nov 10 [cited 2022 Sep 14];38(10):1323-33. Available from: <https://doi.org/10.2224/sbp.2010.38.10.1323>.

86. The Mental Health of People with Disabilities [Internet]. Centers for Disease Control and Prevention; 2020 Nov 30 [cited 2022 Oct 10]. Available from: <https://www.cdc.gov/ncbddd/disabilityandhealth/features/mental-health-for-all.html>.

difficult, and this exacerbates financial difficulties. Several TB survivors mentioned losing out on work years while recovering from TB. One person could not work for four years after being cured. Caregivers also often lose employment. TB, besides resulting in large out-of-pocket expenditures, also reduces the earning capacity of those most affected.

TB and its Impact on Nutrition: Maintaining nutrition levels is important but expensive. TB susceptibility in India has been attributed to malnutrition.

"I didn't stop taking medicine even if I was unable to eat food. Sometimes when I begged people for money to buy food and medicines, they wouldn't give me."

- TB survivor

Two people, SS and PL, spoke about the need for cooked food rather than rations.

"They give ration but without gas - how will we use the ration?"

Nutritional needs do not end with the completion of treatment. Maintaining good nutrition post-TB treatment is critical.

"Even now, I have to take dry fruits and it's very expensive. Some people right after completing the medicine, they think that they are okay. They don't need to take the nutritional diet, but I recommend they also take care of their diet after completing the medicine, because there are lots of side effects."

- TB survivor

The recently launched Nikshay Mitra scheme can be expanded to supporting TB survivors and their nutritional needs.

Recommendations:

- Ensure improved counselling services to address physical, mental, social and economic needs of people with TB and their families.
- Develop specific counselling modules for people with disabilities who are diagnosed with TB and their caregivers. Consider including quality of life questions such as "are there any problems you face at home?," and "have you been able to get back to work after treatment?" (during post treatment follow-up)
- Ensure implementation of the NTEP's Strategy to End Stigma and Discrimination Associated with Tuberculosis and the recently launched Family Care model for proper sensitisation of family members and caregivers. Consider specialised training on TB for family members of people with disabilities who are diagnosed with TB.
- Strengthen delivery of nutritional support through Nikshay Poshan Yojana and Nikshay Mitra schemes. Consider making available nutritional support in kind for people with disabilities who are on treatment for TB.

4.2 Life after TB

TB disrupts normal life, even after 'cure'. Because of the consuming nature of the disease, and the toll it takes on the physical health of the infected, several people find it difficult to return to their pre-TB quality of life. For some, education is disrupted. For others, they are unable to return to work or find jobs once again. Having to navigate this "new normalcy" involves dealing with a host of challenges, including coping with mental health issues, disabilities and side-effects of TB drugs, facing economic constraints and difficulties in resuming/finding work, and being met with insensitive societal attitudes.

Long-term impact on physical health

TB survivors often face lifelong disabilities.⁸⁷ Comorbidities also continue to persist. Those interviewed for this rapid assessment included two PwTB who acquired hearing loss, two PwTB who acquired visual impairment and one PwTB who was left paralysed on one side. However, these disabilities persist even after completing TB treatment and can be considered permanent disabilities, and require special attention. Learning to live with disabilities during adulthood is especially challenging.

CB, who underwent treatment for Brain TB, now lives with a paralysed leg. Despite being cured of TB, her disability prevents her from leading a normal life. Her paralysed leg makes it difficult for her to go outside her house without support. EL, a 54-year-old man from Tamil Nadu became visually impaired - his TB treatment is currently on hold as he is undergoing treatment for restoration of his vision. However, the long-term impact on his vision is unknown at this point. AMT was left visually impaired from Brain TB and has developed a squint. MA, a 39-year-old woman from Odisha, suffers from hearing impairment due to MDR-TB and XDR-TB.

"This has had a big impact on my life. Even with hearing aids, I cannot hear anything. I am unable to listen to the voice of my child."

Disability experiences vary based on socio-economic status, type of employment and age. Another TB survivor and health advocate had her "normal life" disrupted by her disability.

"Things that I used to take for granted got affected. I always used to listen to music with my earphones, and suddenly, I couldn't do that. I was looking at a life of complete dependency on someone for even small things. I was very scared because of this and how it would affect my professional career. I used to live a very independent life and suddenly I was dependent on my parents. For 6-7 years, everything was completely silent for me, and then I got my cochlear implants done at the end of 2018. Cochlear implants also come with challenges of adjusting and familiarising."

MO still suffers from muscle and joint pain in her neck, as well as hair fall. RK, who completed his treatment a few years ago, still suffers from severe eczema of the skin. PDB, a 37-year-old woman from Sikkim, has been suffering from insomnia even after treatment completion. For MA, life looks a lot different now in comparison to what it was before the onset of the disease. Her skin has become black; she has liver cirrhosis, and finds it difficult to walk even a short distance due to one of her lungs being severely damaged.

87. Menzies NA, Quaife M, Allwood BW, Byrne AL, Coussens AK, Harries AD, et al. Lifetime burden of disease due to incident tuberculosis: A global reappraisal including post-tuberculosis sequelae. *The Lancet Global Health* [Internet]. 2021 Dec 1 [cited 2022 Sep 14];9(12):E1679-E1687. Available from: [https://doi.org/10.1016/S2214-109X\(21\)00367-3](https://doi.org/10.1016/S2214-109X(21)00367-3).

Need for Physical Rehabilitation: Tackling the long-term effects and comorbidities of TB requires rehabilitation. CB and SS underwent extensive physiotherapy. CB has paralysis due to brain TB and SS has paralysis limiting her mobility.

"We need to have an expert consensus meeting at the national-level including all the disciplines – not just health, but others too, like social and psychological rehabilitation. We need customised programmes based on individual needs. In the case of DR-TB, we need to look at pulmonary rehabilitation."

- WHO Consultant

This requires creating strong partnerships with other departments, both within and beyond the Health Ministry.

"We already have linkages with the HIV and diabetes programme and drug de addiction ministries. We need to have it with the disability department as well."

- TB Programme Implementer

Need for expanded counselling for disabilities: Experts emphasised the need for peer support to help TB survivors cope with disabilities. This is especially required for those who are elderly and abandoned by their families due to TB.

"We had a patient, a young girl who was very smart in studies, but due to side effects of injectables, she suffered hearing loss. Now she doesn't talk and thinks that she will never get cured. We are trying to set up a support group meeting to address these kinds of problems."

- TB Programme Implementer

The healthcare system is still under-equipped to deal with the aftermath of TB such as disability and the poor mental health of those who are undergoing TB treatment. There appears to be inadequate understanding among the medical fraternity for treating mental health-related issues due to TB. PL said that her physician prescribed calcium tablets when she confided that she had suicidal thoughts and RK said the doctors were focused on just examining and prescribing medicines.

"The person who is giving it is not only a doctor but an authority figure. When a patient has trouble, you need to tell us the measures to address it, but they don't give us suggestions to address our suffering or counsel us, they just give medicine and tell us to eat it."

Experts also pointed to the need for occupational rehabilitation and livelihood training, to strengthen different dimensions of a TB survivor's life. In the case of acquired permanent disabilities due to TB, rigorous programmes need to be developed to ensure skill training and to help people cope with their disabilities. Additionally, sensitisation and awareness programmes for the community need to be incorporated as part of the rehabilitation process. Such measures will ensure the development of healthy coping strategies among those living with a long-term sequelae of disease.

"This is one field which we didn't speak about a few years back, but now at least we are talking about it. Maybe in a few years, it will be effective."

- TB Programme Implementer

Long-term impact on mental health

Mental health issues, including severe mental health disorders, persist or surface after the completion of TB treatment.

"When TB medication stopped I also stopped taking medicines for mental illness. I was absolutely fine for two to three years after that, but again suddenly I used to get very angry at small things. Again the symptoms started, I began suspecting people all the time."

- TB survivor

Although TB has adversely affected mental health during the treatment phase, we found that TB survivors developed resilience as a result of facing many challenges. AK lost his job at a global chain of hotels due to TB. He is currently working as a TB Champion to support himself. Despite a change in employment, he is proud of having faced the challenge of TB and overcoming it.

"I don't feel regret that I have lost my job, the time I have spent and suffered makes me feel pride, I never feel that luck has left me or jobs have been lost. If I received the right direction, it might have been better so that's why I'm feeling good that I'm doing this work."

MA testified that even when she lost her hearing she never stopped taking medication.

"Because I want to become fully cured. So I continued my medicine after different side effects also. Because if I become cured of TB then you can also live a life. If you are afraid of taking medicine then you will never be cured."

Need to address gendered stigma due to TB and disabilities: While it is common for people with TB to face stigma during their treatment, women TB survivors reported continuing to face stigma long after treatment completion. CB and MA were married women but have now been abandoned by their spouses.

"Due to this problem (TB), people on my father-in-law's side are not accepting me and now a divorce case is going in the civil court. My two children are staying at my parents [place]."

CB suffered a total loss of memory during treatment. She was pregnant at the time but as she fell into a coma, her child was aborted. Her husband who was initially supportive, abandoned her as her condition worsened.

"In six months he changed completely, he left me; he left me with my parents. I was full of emotion, you try to move forward, you leave people who leave you."

Five PwTB reported facing stigma because of their TB acquired disability. CB admitted to being mocked because of her limp, but she braves their taunts.

"The stigma made me want to do better, I will get better and show them. An elder brother came and said, oh she can't walk, that especially made me want to become better."

- TB survivor with a disability

The experiences of those living with disabilities in urban areas were quite different. The health advocate who lives with a hearing impairment, says that while she was able to join support groups to help her cope with life after TB, they have some limitations when it comes to disability.

"Disability is not very openly spoken about even in the support groups because there is some hesitancy to speak about things like disability."

Visible morbidities among TB survivors also make them targets of stigma. RK suffers from severe eczema, which continues to persist after his recovery from TB. He also found people he met to be insensitive. His wife and father left him when he contracted TB. Although they returned after he got cured, he does not receive any real support from them.

Long-term impact on economic health

Several TB survivors continue to face increased expenditure even after being cured of the disease. Several TB survivors interviewed mentioned having lost their jobs or having to find alternate employment either due to work years lost or because of the debilitating effects of the disease. Some of them have found solace in the TB Champions programme run by the NTEP through partners such as REACH.

Five PwTB we interviewed are currently working with REACH as TB Champions to meet their daily expenses. AK, a 28-year-old male from Bihar, was working in a tier-1 city for a global hotel chain before he was infected with TB. Post infection, he had to quit his job and move back to his hometown in Bihar. His unemployment status during the course of his treatment affected him mentally, and he was worried about starting from scratch after being cured. While TV was employed with a reputed MNC, he suffered from a comorbidity which eventually led to him contracting TB. He is now undergoing treatment for the comorbidity and working as a TB Champion. PL, who also works as a TB Champion, said that she wanted to take this on to ensure that others are not as lost as she was during her treatment.

"If I received the right guidance it might have been better so that's why I'm feeling good that I'm doing this work."

AMT, a brain TB survivor who lost vision in one eye, is also working as a TB Champion.

"I want the things that happened to me not to happen with someone else, so any people with TB I meet, I ask them not to get scared and especially those with brain TB I ask them to pay attention to their eyes."

Another TB survivor was about to start employment when she contracted TB. She found it difficult to transition back to work after years of treatment. Her confidence was broken because her peers had gone far ahead of her in terms of professional experience. Her experience in her first workplace post treatment showed that Indian companies are still not inclusive of PwD.

"I was the first person in my workplace with a disability. Because of my hearing loss, there was very little interaction with my colleagues. There would be meetings that went on for one hour and after it was over, I would be briefed in just 10 minutes. In the first few months, even seeing people picking up a call was very triggering for me. Because of this, I felt my opportunities were limited and that I had reached a point of stagnation. Group conversations are still a challenge for me since it is difficult for me to grasp each and every person's conversation."

RK couldn't complete his higher education because of TB. He is currently working, but inconsistently, since he has to take medication.

"I am working in the TB programme and I do other jobs here and there but I find it very hard to work. In both my hands, and legs, I have eczema, which during heat bursts leaving behind sores that hurt a lot, then I have to stop the work."

TB leaves survivors with side effects and disabilities that are often expensive to mitigate. Three PwTB faced the burden of continued medical expenses post TB. SS spends Rs. 300 on every physiotherapy session, whereas CB spends Rs 3,000 on physiotherapy per month as well as an additional Rs. 7000 on other medical expenses even as she is cured of TB. She works two jobs, but can only make Rs. 5,000 per month. Another TB survivor spoke about how she needed a nurse and intravenous fluids even after getting discharged from the hospital.

As TB left a dent on the life savings of survivors, some of them tried applying for State Government Disability schemes. KU and SV, both residents of Tamil Nadu who had previously applied to the Tamil Nadu Government State Pension Scheme, were discouraged from continuing the process because of the complicated procedures. However, they were in need of the pension as they did not have stable incomes and also had to meet continued medical and nutrition expenses. KU is still hopeful that he will be able to recover the expenses.

"I applied for a scheme for disability benefits in 2013, many formalities were required. It was a scheme with 15% disabilities for which you get Rs. 1,000 (per month). I had a job then and couldn't run pillar to post for that so I let it be but I have been encouraged to reapply, I leave it up to God whatever he wishes."

He also talked about specific challenges in employment for PwD.

"I asked for a job but they pity us for being disabled and give only charity. I don't want that, I want to work and earn money. Now I am unable to work so I am dependent on my siblings but now they are not there for me so I am a little upset. I would be very grateful if I got a job."

Need for Programmatic follow-up inclusive of disability

Being cured of TB does not mean all is well. Those who are cured have weak immune systems, have a propensity to develop post-TB sequelae and become reinfected with TB. One PwTB and one PwD reported reinfection with TB. An ongoing project on post-treatment follow-up observed a 4.3% recurrence rate and 5.5% post treatment fatality rate in a pool of 30,000 people who had completed treatment. Around half of those followed-up experienced some sort of pulmonary dysfunction, even after the microbiological cure, which ranges from minor abnormalities in breathing patterns to severe breathlessness.

The NTEP has a post-treatment follow-up plan as part of the National Strategic Plan for TB Elimination, for six months, 12 months, 18 months and 24 months after treatment. This is being scaled up across the country; at present, implementation remains uneven. Several experts pointed out challenges in ensuring proper follow-up, particularly when people migrate for work, or with those who were treated in the private sector.

“Once treatment is over, people are dropped from the system. They should be followed up for relapse as well as the disability they might have for a lifetime.”

- Chest Physician

People with TB and their families are also not aware of the follow-up system.

“I did not know that I had to follow up until I became a TB Champion.”

Two doctors mentioned that TB survivors do not come back after six months of treatment completion, despite being asked to do so. Only when there is a relapse of symptoms do they consider consulting a doctor again. They attribute the lack of follow-up to two broad factors: human resource scarcity and reluctance of TB survivors to return to the health system once declared cured.

“Performance wise, there is a wide variation depending on the geographies. Some districts do one follow-up, some more than two. The supervisors often don't find time to do this.”

- TB Programme Implementer

Recommendations:

- Strengthen and institutionalise a robust post-treatment follow-up mechanism for TB survivors, including in persons with disabilities and those who have recently acquired disabilities due to TB
- Incorporate identification and classification of disabilities within post-treatment follow-up
- Engage trained TB survivors to undertake post-treatment follow-up and provide continuum of peer support and counselling through one-to-one contacts and support groups

- Develop and make available physical rehabilitation programmes and centres, particularly for pulmonary rehabilitation. Build linkages with existing rehabilitation centres under the NHM.
- Introduce occupational rehabilitation for TB survivors including physiotherapy services
- Ensure availability of continued nutritional support for TB survivors with disabilities
- Expand availability of and access to disability support schemes, including for housing, disability aids and other support services

5. Summary of Recommendations

This section summarises the recommendations in the various sections of this report.

Structural Recommendations

- **Mainstream disability into healthcare programmes.** Disability is a cross-cutting issue that needs to be mainstreamed into public health programmes. The systems and policies for the care of persons with disabilities or for treating diseases that cause disability have to be mainstreamed i.e., policies need to be more inclusive. This can only come with a structural change at all levels.
- **Make decision-making bodies more inclusive.** The absence of specialised treatment for people with disabilities has been linked to the lack of acknowledgement of disability as a consideration in designing public health systems. Measures must be taken to bring intersectional conversations on public health and disability to the forefront, including enabling the healthcare system to attend to the needs of PwD. Active screening and contact tracing among PwD will help bring more PwD into the system. These considerations are often left out of the mainstream healthcare narrative due to the absence of persons with disability in decision-making bodies. Having people with lived experiences of disability in the core decision-making bodies will ensure that the concerns of PwD are taken into account.
- **Make health centres more accessible.** PwD are deterred from accessing hospitals and other healthcare centres since most of them are not accessible to disabled persons. Measures like installing ramps, at least at district-level facilities to begin with, having medical/paramedical staff who can interpret sign language etc. will make the healthcare system more inclusive.
- Consider **amending the Rights of Persons with Disabilities Act, 2016 to include heart and lung disabilities/functional disabilities**, either directly or via a separate enactment such as the HIV and AIDS Act

Programmatic Recommendations for the NTEP

Cross-cutting:

- Incorporate a **focus on disability into all aspects of the TB response**, including in the development of new tools, policies and strategies and in their implementation.
- **Prioritise person-centred care for people with disabilities diagnosed with TB.** The lived experience of every person with TB is different. Even in our small interview pool of 18, no

two persons had the same experience. Hence, the care they require also varies. Making the care cascade person-centred rather than disease- or system-centred will help target individual needs, thus resulting in better outcomes. This includes home delivery of drugs and state funded transportation to the treatment centres.

- **Ensure Micro-planning for people with disabilities.** Experts have unequivocally stated that the effects of TB are doubled or tripled for PwD. Micro-planning for PwD who contract TB will help in addressing the special ways in which the disease affects them. The Ministry of Health and Family Welfare and the Ministry of Tribal Affairs has jointly brought out a Tribal TB Initiative to improve the cascade of care for tribal populations in India. A similar joint initiative by the Health Ministry and the Ministry for Social Justice and Empowerment for disabled persons will go a long way in addressing the specific needs of this population.
- **Address disability-related data gaps.** As previously mentioned, ensure the inclusion of disability as a variable in Nikshay, both at the time of diagnosis and during post-treatment follow-up.
- **Engage communities and civil society in providing effective care and support to people with disabilities.** Building local synergies between the TB programme and disability groups can be a first step; local civil society organisations working on disability can be invited to become members of TB Forums.

Diagnosis:

- **Reduce delays in diagnosis,** including by improving health seeking behaviour, to prevent sequelae
- **Strengthen sputum collection and transportation/use of mobile diagnostic units** to reduce physical access challenges
- Sensitise and train healthcare workers to **fast-track diagnosis among people with disabilities**
- Ensure **active case-finding among institutions and centres for people with disabilities**

Treatment:

- **Include Disability as an individual-level variable on Nikshay.** All people with TB registered on Nikshay are given a TB Identity Card and a TB Treatment Card under the NTEP. Inclusion of a column on the pre-existence of a disability and the type of disability will help track TB-related sequelae, thus making it easier to monitor and address specific problems faced by this population. This will also facilitate the tracking of people with disabilities who are diagnosed with TB and enter the care cascade. This one action can greatly expand the availability of data and information on TB and disability including treatment outcomes, mortality, comorbidities etc.
- Develop and establish a **robust surveillance system for identification of adverse drug reactions and side-effects,** as part of routine treatment support.
- Develop and disseminate clear **guidelines on how TB-related complications are to be addressed** and streamline referral systems for management of complications within public and private healthcare facilities. These referrals include but are not limited to TB-related surgeries, eye-care, rehabilitation and prosthetics and orthotic facilities, and additional nutritional support.
- Expand and make widely available **combination of person-centred care with peer support**

and use of technology/artificial intelligence to monitor and minimise impact of side-effects for people on treatment, to minimise drug-reactions.

- Ensure **treatment literacy for all people on treatment and their families,** particularly on potential side effects. Several people with TB interviewed mentioned that they were not aware of the potential side effects of the treatment, and would have been more vigilant and sought medical care sooner if they had known. The potential side effects of the drugs must be communicated effectively and sensitively to people with TB so that they are aware of its consequences, but are not deterred from treatment completion out of fear.

Other health and socio-economic dimensions

- Ensure **improved counselling services** to address physical, mental, social and economic needs of people with TB and their families.
- Develop **specific counselling modules for people with disabilities who are diagnosed with TB and their caregivers.** Consider including quality of life questions such as “are there any problems you face at home?” and “have you been able to get back to work after treatment?” (during post treatment follow-up)
- Ensure effective implementation of the NTEP’s Strategy to End Stigma and Discrimination Associated with Tuberculosis and the recently launched **Family Care model for proper sensitisation of family members and caregivers.**
- Consider **specialised training on TB for family members of people with disabilities who are diagnosed with TB.**
- Strengthen delivery of nutritional support through Nikshay Poshan Yojana and Nikshay Mitra schemes. Consider making available nutritional support in kind for people with disabilities who are on treatment for TB.
- **Undertake active outreach to people with disabilities.** A major problem identified by the experts was the lack of visibility of persons with disabilities in the healthcare system due to reasons such as difficulty in accessibility and reluctance to approach the system. Empowering PwD through education and awareness is essential to improve their trust in the public health system.

Life after TB: for TB survivors

- Strengthen and **institutionalise a robust post-treatment follow-up mechanism** for TB survivors, including in persons with disabilities and those who have recently acquired disabilities due to TB
- Incorporate **identification and classification of disabilities** within post-treatment follow-up
- Engage **trained TB survivors to undertake post-treatment follow-up** and provide continuum of peer support and counselling through one-to-one contacts and support groups
- Develop and **make available physical rehabilitation programmes** and centres, particularly for pulmonary rehabilitation. Build linkages with existing rehabilitation centres under the NHM.
- Introduce **occupational rehabilitation for TB survivors** including physiotherapy services and livelihood training
- Ensure **availability of continued nutritional support for TB survivors with disabilities**
- Expand **access to and availability of disability support schemes,** including for housing, disability aids and other support services

6. Conclusion and Way Forward

India is currently at an inflection point with regard to its public health systems, which demonstrated both vulnerabilities and resilience during the COVID-19 pandemic. There are now various initiatives to digitise health service delivery in India such as the Ayushman Bharat Digital Mission (ABDM) which aims to create a national digital health ecosystem that supports universal health coverage in an efficient, accessible, inclusive, affordable, timely and safe manner. Similarly, the United Health Interface (UHI) is envisioned as an open protocol for various digital health services including tele-medicine. The National Disability Health Policy (2022)⁸⁸ also recognises that it is crucial to close data gaps in disability in India and takes a digital-data approach. The Draft National Policy for Persons with Disabilities advocates for a centralised disability identity card – Universal Disability Identity (UDID) – that would form the basis of mapping service delivery and entitlements for people with disability in India. The TB programme, which is already data-rich, is working in mission mode, backed by the highest political commitment. Overall, there is a strong enabling environment to strengthen linkages between our responses to TB and disability in India.

This rapid assessment has reaffirmed that long-term and short-term disabilities are a potential outcome of TB; the scale and extent remain unknown. India's draft National Policy for Persons with Disabilities^{1,2,4} highlights the need for strengthening preventive measures to reduce disabilities. Since TB is known to be curable and treatable⁸⁹, it would be important to include preventive measures by improving socio-economic and health-related outcomes to reduce the long-term burden of disease on the individual and the nation. It is crucial to track disability outcomes of the disease to first establish the scale of the various types of disabilities that TB results in, before policy can respond to the challenges presented. Without a committed strategy for collecting data on disability outcomes of TB, neither practitioners nor policy makers can tackle the challenge effectively.

In the case of people with disabilities who constitute about 7% (World Bank, 2007) of the population (conservative estimate), India's public health system needs to adopt inclusive approaches so that people with disabilities do not fall through the cracks. Currently, people with disabilities are invisible, as is data that offers insights on their access to health care. Specifically, access to health presents several issues confronting people with disabilities: challenges in commuting to the point of care; communicating with healthcare providers; coping with mental health needs; navigating disability-related stigma; being able to afford high-quality health care, whether in the public or private sectors; and poor awareness to advocate for and demand their entitlements. More research is urgently required to strengthen our understanding and steer tangible change for people with TB and disabilities. It is incumbent upon all of us – policymakers, programme designers, implementers, clinicians, community leaders – to reimagine public health and TB policies from a disability-inclusive lens.

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Annexures

Annexure 1: Govt. of India Disability Related Schemes across education, infrastructure, health and employment indices

S.No.	SCHEME	OBJECTIVES
1	SPIDA (Scheme for Implementation of Rights of Persons with Disabilities)	<p>This is an umbrella scheme containing sub-schemes. Mainly seeks to provide financial assistance (GIA) to state governments, various bodies set up by the Central and State governments including autonomous bodies and Universities, to carry out the implementation of various activities specified in the RPWD Act, 1955. Its objectives, among others, include:</p> <ul style="list-style-type: none"> To enhance the accessibility of the built environment, transport system and information and communication ecosystem. To assist State Governments to organise camps for issuance of disability certificates. To create awareness campaigns and sensitisation programmes for various stakeholders and other Information Education Communication. To set up/support resource centres facilitating dissemination of information on disability issues, counselling and providing support services. Supporting activities relating to pre-school training for children with disabilities, counselling for the parents, training for caregivers, teachers training programme and activities relating to early detection camps for children of age zero to five years and early intervention. To establish early diagnostic and intervention centres at District Headquarters/other places having Government Medical Colleges, with a view to help hearing impaired infants and young children to acquire necessary skills to get prepared for regular schooling. Identification and Survey/Universal ID of PwD.
2	ACCESSIBLE INDIA CAMPAIGN	<p>Nation-wide Campaign for achieving universal accessibility for Persons with Disabilities (PwD) and a sub-scheme under SPIDA. Three important verticals:</p> <ul style="list-style-type: none"> Building Environment Accessibility: Enhancing the proportion of accessible government buildings Transportation Accessibility System: Enhancing proportion of accessible airports. Enhancing the proportion of accessible railway stations. Enhancing the proportion of accessible Public Transport. ICT Ecosystem Accessibility: Enhancing proportion of accessible and usable public documents and websites that meet internationally recognised accessibility standards. Enhancing the pool of sign language interpreters. Enhancing the proportion of daily captioning and sign-language interpretation of public television news programmes.

S.No.	SCHEME	OBJECTIVES
3	BRILLE PRESS SCHEME	A Central Sector Scheme to provide Braille material and literature to the Persons with Visual Disabilities in India. Is also a sub-scheme under SPIDA.
4	UNIQUE DISABILITY ID	Issue UDID to every person with disabilities in order to <ul style="list-style-type: none"> • Create a National Database for PwD • Encourage transparency, efficiency and ease in delivering welfare benefits to PwD • Enable tracking of physical and financial progress of the beneficiary at all governmental levels. • Ensure online availability of data of Persons with Disabilities across the country through a centralised web application. • Quick Assessment process for calculating the percentage of disability by the hospitals/ Medical Board. • Non-duplication of PwD data. • Online renewal and update of information by Person with Disabilities/ on their behalf • Effective management including interoperability of the benefits / schemes launched by the Government for PwD
5	NATIONAL ACTION PLAN FOR SKILL TRAINING OF PwD	<ul style="list-style-type: none"> • Enable PwD to develop their employable skills and enhance their prospects for meaningful employment. • Applies to PwD with benchmark disabilities and having a disability certificate to this effect issued by a competent medical authority. • As an endeavour to encourage women, 30% of the total intake of each training programme shall be reserved for women candidates. • The skill training will be provided through training institutions recognised by this Department as per the eligibility conditions contained herein.
6	ASSISTANCE TO DISABLED PERSONS FOR PURCHASE/ FITTING OF AIDS AND APPLIANCES	The scheme is centrally aided and implemented through voluntary organisations. NGOs seeking to provide such assistance can apply for grants under this scheme through the Dist. Disabled Welfare Officer. Such assistance will cover aids costing not less than Rs.50/- and more than Rs.6000/-. While a PwD with a monthly income of Rs. 5000 will be entitled to full subsidy, a PwD with a monthly income between Rs. 5000-8000 will be entitled to 50% subsidy of the cost . Traveling, boarding and lodging costs are also covered.
7	DEEN DAYAL REHABILITATION SCHEME	This Scheme of the Ministry of Social Justice & Empowerment, Government of India, simplifies and facilitates procedure for easy access to govt. support for NGOs with the aim to widen the scope and range of programmes for the benefit of PwD.
8	INCENTIVES TO PRIVATE SECTOR EMPLOYERS FOR PROVIDING EMPLOYMENT TO PERSONS WITH DISABILITIES	The scheme covers employees with disabilities earning a salary up to Rs. 25,000/- per month working in the private sector. The government will pay the employer's contribution to EPF and ESI for the first three years. The Ministry of Social Justice and Empowerment will provide lump-sum funds to the EPFO and the ESIC out of which such contributions by the government on behalf of the employer shall be made. These funds will be replenished periodically.

S.No.	SCHEME	OBJECTIVES
9	NIRAMAYA SCHEME	This scheme provides up to Rs. one lakh health insurance coverage to persons with disabilities covered within the ambit of the National Trust Act, at an affordable premium regardless of the type of disability covered within the National Trust Act. This insurance does not require the beneficiary to undergo any prior medical tests to avail such health insurance. This health insurance shall cover the avilment of any of the following health services: <ul style="list-style-type: none"> • Facility for OPD treatment including the medicines, pathology, diagnostic tests, etc. • Regular Medical checkup for non-ailing disabled • Dental Preventive Dentistry • Surgery to prevent further aggravation of disability • Non- Surgical/Hospitalisation • Corrective Surgeries for existing Disability including congenital disability • Ongoing Therapies to reduce impact of disability and disability related complications • Alternative Medicine
10	SAHYOGI (CARE ASSOCIATE TRAINING SCHEME)	This scheme contemplates the setting up of care associate cells which will dispense care-giving training to families and care associates of persons with disabilities covered under the National Trust Act. The training shall involve two levels, viz., primary and advanced. The course modules have been prepared by the Rehabilitation Council of India.
11	SAMBHAV (AIDS AND ASSISTIVE DEVICES SCHEME)	The scheme entails the establishment of Sambhav Resource Centre. These resource centres will contain information about various aids and assistive devices for persons with disabilities covered under the National Trust Act. Such centres will also demonstrate how such devices are meant to be used and will construct model bedrooms, bathrooms and kitchens wherein these devices are installed. They should also display a list of such aids and devices and their corresponding costs.
12	BHADTE KADAM (AWARENESS SCHEME)	This scheme obligates registered organisations to raise awareness and sensitisation about disabilities covered under the National Trust Act to people's representatives, government personnel, medical fraternity, legal professionals, banks and financial institutions, educational institutions including students and teachers, families and guardians of PwD, and NGOs.
13	SWAVLAMBAN HEALTH INSURANCE SCHEME	This scheme is a MoU between the Department of Empowerment of People with Disabilities, Ministry of Social Justice and Empowerment, and The New India Assurance Company Limited to provide a comprehensive and affordable Health Insurance Scheme for PwD. This scheme provides health insurance cover to a beneficiary, whose annual income is less than Rs. 3 lakhs per annum and is aged between 18 years and 65 years. The insurance cover will include the PwD and their family (spouse and up to two children). The scheme also ensures coverage of any pre-existing condition and a health Insurance cover up to Rs. 2 lakhs per annum as family floater. It will not require a premedical check-up. The scheme will be implemented through active participation of the National Institutes and Composite Regional Centres for Persons with Disabilities (CRCs) under the DEPwD, MOSJ&E.

Annexure 2: Sample Population Details

Participant Code	Age	Gender	Type of TB*	Type of Disability
Persons with Tuberculosis				
TV	33	Male	Drug-sensitive pulmonary TB	Long-term kidney issues
MO	30	Female	Drug-resistant TB	Locomotor disability
AMT	42	Female	Drug-sensitive Brain TB	Visual impairment
PDB	37	Female	Drug-resistant TB	Sleep deprivation, hearing issues and burning sensation in left chest
EL	54	Male	Drug-sensitive pulmonary TB	Visual impairment
SS	23	Female	Drug-sensitive pulmonary TB	Tinnitus, Peripheral neuropathy
PL	23	Female	Drug-resistant TB	Blurred vision and decrease in visual acuity
MA	39	Female	Drug-resistant TB	Complete hearing loss
CB	27	Female	Drug-sensitive Brain TB	Paralysis of one side
RK	29	Male	Drug-resistant TB	Skin diseases and wounds
AK	28	Male	Drug-resistant TB	Mental illness
CH	55	Female	Drug-sensitive pulmonary TB	Unknown
Persons with Disabilities				
SV	40	Female	Extra-pulmonary TB	Poliomyelitis
VK	49	Male	Drug-sensitive pulmonary TB	Poliomyelitis
KU	51	Male	Drug-sensitive pulmonary TB	Poliomyelitis
SK	16	Male	Drug-sensitive pulmonary TB	Down's Syndrome
SJ	21	Male	Drug-resistant TB	Visual impairment from birth

Annexure 3: Interview Questionnaires

[I] Sample Population

Persons with TB and Disability

1. What is your age?
2. What gender do you identify with?
3. What is your educational qualification?
4. What work do you do?
5. Can you describe your economic level? Family income?
6. Can you talk about your history with TB?
 - a. When did you first notice symptoms?
 - b. What type of TB did you have? (Pulmonary/extrapulmonary/latent/MDR-TB)
 - c. Do you have other co-infections or comorbidities such as HIV, diabetes?
 - d. Have you been reinfected with TB?
7. Can you talk about your treatment history?
 - a. Where did you seek medical attention?
 - b. If possible, can you describe your medication regimen?
 - c. How long was your medication regimen?
 - d. Did you complete the TB medication regimen?
 - e. How did you pay for your treatment?
 - f. Have there been follow-ups? If yes, how and at what frequency?
 - g. Have you been supported by an NGO through the care cascade?
8. Can you tell me how TB affected you after you were diagnosed and before the setting in of difficulties due to the disease?
 - a. Physically, Mentally/emotionally, Socially, Economically/financially
9. Can you talk about any long-term effects of TB you have?
 - a. Were you told about the side-effects of treatment or the possibility of a disability during your treatment?
 - b. Physically, mentally, emotionally, socially, economically/financially
 - c. Did you seek any medical aid or therapy?
 - d. How has the government supported you?
10. How do you feel your life has changed since you contracted TB?
 - a. What are some of the everyday struggles you face?
 - b. Have you faced stigma due to the disease? Can you talk about it?
 - c. Have you been perceived differently because of TB and/or its sequelae?
11. Can you talk about some of the challenges you faced in the healthcare system while seeking care for/support post TB?
12. Have you received government aid during or after treatment?
 - a. What type of aid did you get?
 - b. Can you talk about any challenges (if at all) you faced in receiving the aid?
13. How would you like the government to support you further?
14. Would you like to tell me anything more about your experiences with TB or regarding treatment/support required?

Persons with Disability and TB

1. What is your age?
2. What gender do you identify with?
3. What type of disability do you have?
4. What is your educational qualification?
5. What work do you do?
6. Can you describe your economic level?
7. Have you contracted TB?
 - a. Can you talk about your experience with the disease?
 - i. When did you first notice symptoms?
 - ii. What type of TB did you have? (Pulmonary/extrapulmonary/latent/MDR-TB)
 - iii. Do you have other co-infections or comorbidities such as HIV or diabetes mellitus?
 - iv. Have you been reinfected?
8. Can you talk about your experiences in care from diagnosis to treatment?
 - a. When did you seek medical attention?
 - b. Whom did you see for diagnosis?
 - c. Where did you seek treatment?
 - d. How long was your medication regimen?
 - e. Did you complete the TB medication regimen?
 - f. How did you pay for your treatment?
 - g. Have you had follow-ups? If yes, how and at what frequency?
 - h. Have you been supported by an NGO through the care cascade?
9. Can you tell me how TB affected you after you were diagnosed and before the setting of difficulties due to the disease?
 - a. Physically, Mentally/emotionally, Socially, Economically/financially
10. Can you talk about any long-term effects of TB you have?
 - a. Were you told about the side-effects of treatment or the possibility of a disability during your treatment?
 - b. Physically, mentally, emotionally, socially, economically/financially
 - c. Did you seek any medical aid or therapy?
 - d. How has the government supported you?
11. How do you feel your life has changed since you contracted TB?
 - a. What are some of the everyday struggles you face besides those you already need to tackle?
 - b. Have you faced TB-related stigma? Can you talk about it?
 - i. Have you been perceived differently because of TB and/or its sequelae?
12. Can you talk about some of the challenges you faced in the healthcare system while seeking care for/support post TB?
13. During your treatment did you receive government aid?
 - a. What type of aid did you get?
 - b. Can you talk about any challenges (if at all) you faced in receiving the aid?
14. How would you like the government to support you further?
15. Would you like to tell me anything more about your experiences with TB or regarding treatment/support required?

[II] TB Experts/Policy Makers

1. What is your current designation and what is the name of the organisation you are affiliated with?
2. Can you please describe your job profile and its connection to TB?
3. How many years are you working in the field of TB?
4. Can you talk about the implementation success of the NTEP so far?
 - a. Public vs. private sector
 - b. Diagnosis, notification, treatment, and follow up
5. India targets the reduction of mortality and incidence of TB by 2025 and its elimination the year 2030-35, can you describe to us where we are at achieving this target?
 - a. What are some of the successes?
 - b. What are some of the challenges that still exist?
6. We do not hear much about the morbidity component of TB particularly in policy documents. Can you talk about some of the long-term effects of TB?
 - a. Physical, emotional, mental, social, or economical – short- and long-term
 - b. How do these lead to disabilities – temporary or permanent? Who designates it as a disability? How does care change for these persons?
 - c. How does the disability impact the person?
 - i. Is there an influence of age/gender/socio-economic status/stigma/comorbidities/coinfections/MDR-TB etc. on the person?
 - d. How can we tackle this issue? Can you talk about some strategies?
7. The NSP (2017-25) describes four domains in improving and strengthening care (Detect-Prevent-Treat-Build). There are mentions of the need for assessing long-term impacts of TB on patients and families in terms of disabilities and connecting them to appropriate rehabilitation schemes. However, there are no guidelines or policy plans yet. Can you talk about whether there is such an intent in the future?
8. There is paucity in the literature regarding the impact of TB on persons with disabilities. From your experience, can you talk about the impact of disease on persons with disabilities?
 - a. What is the immediate and long-term impact on these persons socially, economically, physically, emotionally etc.?
9. What are the existing mechanisms for persons with disabilities in accessing care?
 - a. What kind of challenges do they face in diagnosis to accessing care?
 - b. What are the challenges in treatment? Or in other words, what are the challenges they face in the care cascade?
 - c. Who supports these persons during the active phase of disease?
10. It is known that around 70% of the patients access care from the private sector. However, this is dotted with issues such as high costs for diagnosis and treatment, under or overdiagnosis, and lack of mechanisms to ensure full completion of treatment. How can access to and delivery of the public sector be strengthened such that a greater number of people particularly those belonging to the lower socio-economic strata have access to it?
11. Can you talk about Public-Private-Partnerships (PPPs) for tackling TB – in reducing its mortality and morbidity and in expanding the reach of the care cascade particularly for the vulnerable and minority populations?

12. At present, we have follow ups at 12/18/24 months post treatment? What is the success rate of follow-up? How can we capitalise on this to detect long-term consequences of the disease?
13. Can you tell us about the government support that exists for patients with TB?
 - a. Are there any challenges in distribution of these aids? Can you please describe?
 - b. Can you tell us how these aids/schemes and its distribution can be improved?
 - c. At present there are no linkages to disability schemes, how can we bring about TB-related disability such that these individuals have access to rehabilitative measures/other benefits?
14. Can you tell us how we can better support those affected with TB and persons with disabilities who have been affected by the disease?
15. Would you like to share anything else with us regarding TB or the government's efforts towards tackling the disease particularly in vulnerable populations and its long-term effects?

Additional questions for practising doctors/physicians

- What can we do to prevent disabilities due to TB? Can you tell us about the management of side-effects? Do you talk about side-effect management to your patients?
- Are TB drugs used to treat other neglected communicable diseases?
- What does the medical fraternity feel about the side-effects of the TB drugs? Is there ample literature around it?
- Do doctors caution patients about the side-effects of TB drugs? How much do you advise and what do you advise? Why/why not?
- Are the side-effects mainly due to drugs? If so, what are some reasons?
- Is disability mainly seen in MDR-TB? If so, what are some of the common disabilities due to this and the reasons behind this?

[III] Disability Experts

1. What is your current designation?
2. Can you please describe your job profile?
3. How long have you been working with persons with disabilities?
4. Can you tell us about TB?
5. In your experience, have you come across persons with disabilities being affected by the disease?
 - a. Can you tell us more about how these people are affected?
 - b. What type of TB do they typically have? (Pulmonary/extrapulmonary/latent/MDR-TB)
 - c. In which age group is it commonly seen?
 - d. Is there a particular disability that makes people more vulnerable?
6. How do persons with disabilities access care?
 - a. When do they go for diagnosis?
 - b. Where do they access care?
 - c. Do they complete their treatment regimen?
 - d. Who pays for their care?
 - e. Do they have follow-ups? If yes, how and at what frequency?
7. How does TB affect persons with disabilities during the active phase of the disease, during treatment or in the long-term?

- a. Physically, mentally, emotionally, economically, or socially
8. Can you talk about some of the challenges they face in the healthcare system while seeking care for/support post TB?
9. What kind of support do persons with disabilities with TB receive from the government? Is there a differentiation when someone has TB-related sequelae?
 - a. What are some of the schemes that they typically avail?
 - b. What are some of the challenges in access to disability entitlements?
 - c. Are there any specific schemes that they avail due to TB?
 - d. Is it linked to their disability certificate or UDID and how does TB feature in this?
10. Can you tell us how we can better support persons with disabilities who have been affected by the disease?
11. Would you like to share anything else with us regarding TB or the government's efforts towards tackling the disease particularly in persons with disabilities and its long-term effects on the population?

[IV] TB Programme Implementers

1. What is your current designation?
2. Can you please describe your job profile?
3. How long have you been working in the TB programme?
4. Can you talk about TB and its impact?
5. Can you talk about the implementation success of the NTEP so far?
 - a. Public vs. private sector
 - b. Diagnosis, notification, treatment, and follow up
6. India targets the reduction of mortality and incidence of TB by 2025 and its elimination the year 2030-35, can you describe to us where we are at achieving this target?
 - a. What are some of the successes?
 - b. What are some of the challenges that still exist?
7. We do not hear much about the morbidity component of TB. Can you describe to us some of the long-term impacts of TB?
 - a. Physical, emotional, mental, social, or economical – short- and long-term
 - b. How do these lead to disabilities – temporary or permanent? Who designates it as a disability? How does care change for these persons?
 - c. How does the disability impact the person?
 - i. Is there an influence of age/gender/socio-economic status/stigma/comorbidities/coinfections/MDR-TB etc. on the person?
 - d. What are some of the follow up mechanisms that exist once patients finish their drug regimen? How successful are the follow-ups at 12/18/24 months?
 - e. Are there any support mechanisms in place for these people?
8. How does TB affect persons with disabilities?
 - a. Physical, emotional, mental, social, or economical – short- and long-term
 - b. How do they feature in the care cascade?
 - c. What are some of the challenges they face during and after treatment?
9. Can you tell us about the government support that exists for patients with TB?

- a. Are there any challenges in distribution of these aids? Can you please describe?
 - b. Can you tell us how these aids/schemes and its distribution can be improved?
 - c. At present there are no linkages to disability schemes, how can we bring about TB-related disability such that these individuals have access to rehabilitative measures/other benefits?
10. Can you tell us how we can better support those affected with TB and persons with disabilities who have been affected by the disease?
 11. Would you like to share anything else with us regarding TB or the government's efforts towards tackling the disease particularly in vulnerable populations and its long-term effects?




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

Chennai Office: 194, 1st Floor, Avvai Shanmugam Salai Lane, Off Lloyds Road, Royapettah, Chennai – 600014, **Phone:** 044-4 5565445 / 044-28132099

Delhi Office: BB-5, 1st Floor, Greater Kailash Enclave Part II, New Delhi – 110048. **Phone:** 011- 49055686

 support@reachindia.org.in

 reachindia.org.in

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