

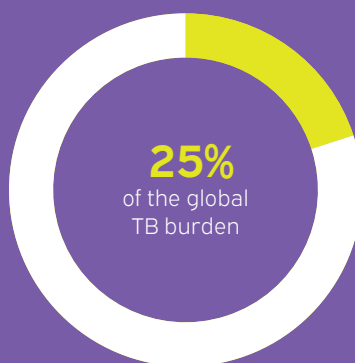
TB AND DISABILITY IN INDIA

Key Insights

INTRODUCTION

India accounts for a quarter of the global Tuberculosis (TB) burden. TB is a complex disease with clinical, social and economic dimensions that intersect to impact people with TB and their families. One such important aspect is disability.

The intersectionality between TB and disability, whether as a pre-existing condition prior to contracting TB or as a consequence of TB, is largely understudied. A pan-India Rapid Assessment was undertaken by REACH through the ALLIES project, with support from USAID, as a first step towards understanding this intersectionality. It focused 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 (PwD) in accessing TB services

The findings of the assessment underscored the urgent need to pay greater attention to the linkages between TB and disability. This brief has been developed with the aim of helping readers better understand the intersections of TB and Disability in India.

WHAT IS THE TB-DISABILITY CONNECTION?

A two-fold intersection:

- An individual's disabilities could increase their vulnerability to TB and make access to TB services more difficult. Existing disabilities could disguise TB symptoms and result in delayed diagnosis.
- An individual could develop a disability – or multiple disabilities – during or as a result of TB treatment, which could mean that despite being cured of TB, a person has the possibility of living with a life-long disability.

WHAT IS DISABILITY?

The Rights of Persons with Disabilities Act, 2016 defines a person with disability as a person with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders their full and effective participation in society equally with others.

In general, people with disabilities remain among the most marginalised groups in India. Their health and health outcomes remain poor.

Empowering people with disabilities with access to accurate information on TB and high-quality TB services is an essential first step.





Multiple scenarios in the journey of a person with TB and Disability:

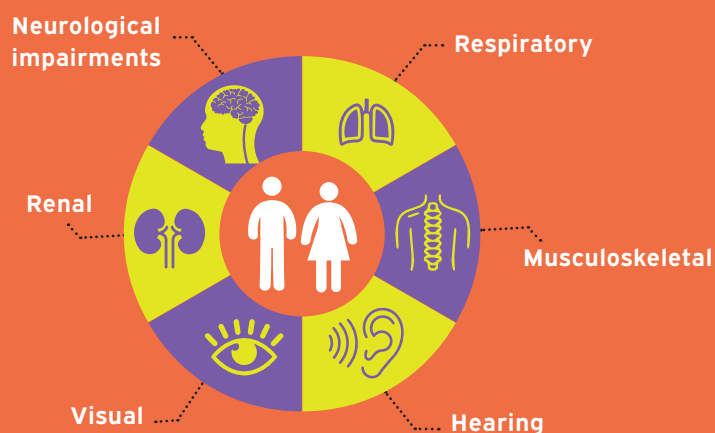
Where an individual enters into TB care with the disability and leaves with the same disability or acquires a new disability along the way.

Where a disability acquired during TB treatment resolves when drugs are discontinued or the treatment regimen is changed.

Where a disability acquired during treatment persists as a lifelong or permanent disability.

Common Disabilities as a Result of TB

It is possible for a person to be fully cured of TB but develop disabilities or live with other health conditions. Respiratory, musculoskeletal, hearing, visual, renal and neurological impairments, and mental health conditions occur most commonly post TB. Lung disability is the most common and also the most severe disability resulting from TB. Other impacts of the disease also include empyema and pulmonary fibrosis, double vision and seizures, among others. TB also has a bearing on health-related quality of life.



TB AND DISABILITY: AN INTERSECTIONAL LENS

Several factors make a person vulnerable and susceptible to TB. Intersectional vulnerabilities play a critical role in determining the quality of life of a person, in case a disability has been acquired due to TB.

Pre-diagnosis – Health Determinants

TB's disproportionate impact: TB affects those coming from lower socio-economic backgrounds. Multidimensionally poor population is 1.82 times more likely to contract TB.

Co-morbidities: Co-morbidities at the time of acquiring TB may directly influence outcomes.

Disability status: Existing disabilities result in a higher predisposition to TB.

Detection and Diagnosis

People with disabilities and diagnosis of TB:

Disabled people are invisible in the overall health system, and therefore, in the TB care cascade. The

diagnostic stage poses additional challenges to them compared to those without disabilities. Delayed diagnosis can increase the likelihood of developing Drug-resistant TB (DRTB).

Treatment and Care

Drug-induced disability: Some anti-TB drugs can lead to drug toxicity, particularly in those with DRTB. Drug-induced side-effects of TB are usually resolvable and do not lead to long-term disabilities. However, the side-effects of second line drugs can be more severe with potential long-term effects.

Economic Effects of TB and TB-related Disabilities

Increased expenditure for families: There is some out-of-pocket expenditure that people with TB need to bear. In addition, this is augmented by the costs of assistive devices or any other aids required if people develop disabilities. Alongside, loss of work exacerbates financial difficulties.

LIFE AFTER TB

Long-term impact on physical health:

Disability experiences vary based on socio-economic status, type of employment and age. TB survivors often face lifelong disabilities and co-morbidities also continue.

Need for physical rehabilitation:

Tackling the long-term effects and co-morbidities of TB requires rehabilitation, which needs strong partnerships with other departments and programmes, both within and beyond the Health Ministry.

Need for expanded counselling for disabilities:

Peer support, occupational rehabilitation and livelihood training are crucial to help TB survivors cope with disabilities. This is especially required for those who are elderly and abandoned by their families due to TB.

Long-term impact on mental health: Mental health issues persist or surface after the completion of TB treatment. Although TB adversely affects mental health during the treatment phase, it needs to be kept in mind that TB survivors also develop resilience as a result of facing many challenges.

Gendered stigma due to TB and disabilities:

Women TB survivors, particularly those with disabilities, continue to face stigma long after completion of treatment.

Long-term impact on economic health: TB leaves survivors with side-effects and disabilities that are often expensive to treat and as a result, several TB survivors continue to face increased expenditure even after being cured of the disease.

Increased chances of re-infection: Despite being cured of TB, people have weak immune systems and a propensity to develop post-TB consequences, and become re-infected with TB.

KEY RECOMMENDATIONS



Cross-cutting Programmatic Recommendations

- Bringing focus on disability in all aspects of TB response
- Prioritising person-centred care for PwD diagnosed with TB
- Ensuring micro-planning for PwD to address special ways in which the disease affects them
- Engaging communities and civil society in providing effective care and support to PwD



Diagnosis and Treatment-related Recommendations

- Including disability as an individual-level variable on Ni-kshay
- Reducing delays in diagnosis and ensuring Active Case Finding (ACF) among PwD
- Establishing a robust surveillance system to identify Adverse Drug Reactions (ADRs) and side-effects
- Developing and disseminating clear guidelines to address TB-related complications
- Monitoring and minimising the impact of side-effects for people on treatment through people-centred care
- Ensuring treatment literacy for all people on treatment and their families

KEY RECOMMENDATIONS



Other Health and Socio-economic Dimensions

- Ensuring improved counselling services to address physical, mental, social and economic needs of people with TB and their families
- Developing specific counselling modules for PwD diagnosed with TB and their caregivers
- Ensuring effective implementation of NTEP's Strategy to End Stigma and Discrimination Associated with TB and the Family Care model for proper sensitisation of family members and caregivers
- Strengthening delivery of nutritional support for PwD on treatment for TB
- Undertaking active outreach and empowering PwD to improve their trust in the public health system



Life after TB

- Institutionalising a robust post-treatment follow-up mechanism for TB survivors, including of PwD and those who have recently acquired disabilities due to TB
- Incorporating identification and classification of disabilities within post-treatment follow-up
- Engaging trained TB survivors to undertake post-treatment follow-up, and providing peer support and counselling through one-to-one contacts and support groups
- Developing and making available physical rehabilitation programmes and centres, and building linkages with existing rehabilitation centres
- Introducing occupational rehabilitation for TB survivors including physiotherapy services and livelihood training
- Ensuring availability of continued nutritional support for TB survivors with disabilities
- Expanding access to and availability of disability support schemes



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

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