World Health Organization

Policy brief on tuberculosis-associated disability

Key messages

- Tuberculosis (TB) is preventable and curable, however, in 2021, an estimated 10.6 million people fell ill with TB worldwide, causing an estimated 1.6 million deaths *(1)*.
- One out of four people who get TB also develop TB-associated disabilities *(2,3,4)* due to impairments worsened by or developed due to the disease and/or its treatment.
- People with TB-associated impairments or disabilities also experience negative implications for health-related quality of life, TB treatment outcomes and life expectancy *(5)*, generating overall negative impacts on the health system.
- The management of TB-associated impairments requires a holistic approach delivered in a timely fashion by a multidisciplinary healthcare team, that includes preventive and rehabilitation services aimed at improving the health and social outcomes of TB-affected people.
- Rehabilitation is an essential health service, which remains inadequately funded, inaccessible or unlinked to TB in most TB high burden countries *(6)*.
- Persons with disabilities are more likely to live in poorer and crowded settings *(6)* and therefore may be more likely to contract TB. Moreover, due to stigma and discrimination, they may face additional barriers to accessing health care services.
- The health and social needs of persons with disabilities, including those with TB-associated disabilities, are well covered under global conventions and frameworks which call for a comprehensive response *(7)*. However, many low- and middle-income countries have limited capacity to address the needs of people with TB-associated disabilities.
- A comprehensive policy response is needed for the treatment and management of TB-associated impairments and disabilities that occur during TB treatment and after its completion. National TB programmes and other programmes responsible for rehabilitation and care for people with disabilities are invited to develop policies to ensure the availability and quality of services addressing the needs of people affected by TB-associated disability, both during and after delivery of TB treatment, by working within and beyond the health sector.
- Further research is urgently needed to inform the development and update of evidence-based policies and guidelines.

Abbreviations

COPD	chronic obstructive pulmonary disease
DR-TB	drug-resistant tuberculosis
GTB	Global Tuberculosis Programme
MAF-TB	Multisectoral Accountability Framework for TB
NCDs	noncommunicable diseases
SDGs	Sustainable Development Goals
UHC	universal health coverage
UN	United Nations
WHO	World Health Organization

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Scope

This policy brief presents evidence on mortality and morbidity during and after TB disease and proposes interventions to address the needs of people with TB-associated disability. The policy brief builds on existing evidence in the areas of TB, TB-comorbidities, TB vulnerable populations, disability and rehabilitation, and is aligned to the WHO published policies and guidance on these topics.

Moreover, the policy brief aims to inform and promote strengthened collaborative actions between national TB programmes and other disease programmes and health systems functions, to deliver people-centred care to individuals experiencing TB-associated impairments and disabilities during and after TB treatment.

This policy brief will serve as a baseline document for the future development of WHO normative products.

How this policy brief was developed

This policy brief was developed based on a review of the literature and informed by stakeholders' input and a scoping review on the interventions to address TB-associated respiratory disability.

Target audience

This policy brief is intended for use by TB stakeholders, as well as the disability and rehabilitation communities. It will be most useful to people working in ministries of health, particularly in national programmes or relevant departments responsible for TB, NCDs, primary health care, nutrition, mental health and substance use, disability and rehabilitation. The policy brief is targeted at policymakers, international technical and funding organizations, researchers, and nongovernmental and civil society organizations, as well as primary care workers, specialist health practitioners and community health workers who support the response to TB, disabilities and rehabilitation in both the public and private sectors.

Background

Tuberculosis (TB) is a preventable and curable infectious disease, yet it still caused an estimated 1.6 million deaths in 2021 *(1)*. Successful treatment is reported in 86% of notifications *(1)*. There is, however, increasing evidence of impairments and disabilities associated with TB *(2,5)*, particularly among people affected by drug-resistant TB *(7)* during and after TB treatment.

25% of people who get TB also develop TB-associated disabilities

In line with the International Classification of Functioning, Disability and Health *(1)*, the term *TB-associated disability* refers to the range of health conditions which, as a result of the illness, the disease and/or its treatment, in interaction with personal and environmental factors, limit the day-to-day physical, social and economic functioning (e.g., walking, self-care, family and community life, and ability to work) of people with TB, and of TB survivors.

Disability results from the interaction of impairments[1] with a range of personal, social and environmental factors, including age, gender, social values, access to infrastructure and policies. TB-associated disabilities can be long-term or temporary and may result from TB disease affecting tissue and organs, adverse reactions to TB medicines, and co-morbid mental disorders, which in interaction with personal and environmental factors, result in activity restrictions and participation limitations *(1)*. The most frequently reported TB-associated impairments affect pulmonary, neurological and mental functions *(7,8)*.

Pulmonary TB, the most common form of TB disease, often causes damage to lung tissue and can result in substantial impairment of lung function, which may continue during treatment and even after the patient is declared cured of TB. The most frequently reported lung conditions include chronic obstructive pulmonary disease (COPD), spirometry abnormalities with obstruction, restriction and mixed patterns, bronchiectasis, pleural thickening, and pulmonary hypertension *(8,9)*.

Extrapulmonary TB, while less common than pulmonary TB, can cause varying forms of impairment and contribute to disability depending on the location and extent of the disease. Spinal TB is an extrapulmonary form of TB, which can result in damage to the bone, disc, joints, and neural structures *(9)*. TB meningitis can cause long-term impairments to brain functioning; this condition occurs more often in children and can cause serious cognitive and behavioural impairment, with consequences that can span the life course.

Adverse reactions to some anti-TB drugs, particularly the currently recommended medicines for drug-resistant TB (DR-TB), may result in visual, renal and neurological impairments, among other organs and systems affected *(3)*.

A recent systematic review and meta-analysis found that TB affects the central nervous system (brain and spinal cord) in more than 4% of TB episodes *(10,11)* and can result in profound mortality and morbidity. Neurological consequences from TB meningitis include seizures, hearing and vision loss, neuromotor

1 WHO defines impairment and disability through the *WHO International Classification of Functioning, Disability and Health*.
Impairment is defined as any loss or abnormality in body structure or physiological function (including mental functions). 'Abnormality' here strictly refers to a significant variation from established statistical norms (i.e. as a deviation from a population mean within measured standard norms) and should be used only in this sense.
Disability is defined as the outcome of the interaction between individuals with a health condition and personal and environmental factors (e.g., negative attitudes, inaccessible transportation and public buildings, and limited social support).

disability, paralysis, cognitive and behavioural impairments and hydrocephalus *(10,12,13)*. Often more subtle sequelae such as cognitive and behavioural impairments may go undiagnosed in children and can have damaging effects on school and subsequently, work performance.

Recognition of TB meningitis-induced disabilities and associated lack of resources to address them is an important component to making equal opportunities for care, rehabilitation, specialised education and employment available.

Mental disorders, such as anxiety and depression, are highly prevalent in people with TB *(9)* and are sometimes associated with the stress of the illness and adverse effects of some medicines, among other factors *(9)*.

TB co-morbidities such as some mental disorders and TB syndemics (e.g. HIV, diabetes, smoking or undernourishment) are likely to be significant contributors to TB-associated impairments and disability *(1,3,4)*. Stigma and discrimination pose additional challenges to individuals with TB-associated disabilities. They may negatively affect an individual's mental health as well as represent a barrier to participation in social and economic activities, as a result of social exclusion *(2)*.

Social and economic impact experienced by people with TB-associated disabilities

TB-associated disabilities may have broader economic and social implications for individuals and households due to a range of barriers they experience in their communities *(3)*.

Economic consequences for individuals include the direct costs of healthcare services and indirect costs associated with travel costs to access care, and time away from productive work with subsequent income loss *(3)*.

Social consequences include difficulties in undertaking daily activities and fulfilling usual social roles in the family and community. Stigma and discrimination may contribute to this, impacting people's ability to return to education, work and community life, and can be exacerbated by a range of barriers in the community *(6)*.

These social and economic consequences can contribute to making people with TB-associated disabilities poorer, more excluded and more vulnerable.

A comprehensive, multi-disciplinary approach is needed to respond to the range of impairments experienced by people during and after TB treatment. However, persons with TB-associated disability may experience barriers in accessing health care and social protection services *(14)*. Therefore, the rigorous provision of integrated patient-centred care is paramount, including access to rehabilitation services and social protection services for people affected by TB, in line with the End TB Strategy *(15)*.

What are rehabilitation services and who commonly delivers them?

Rehabilitation services are those that focus on the functioning of an individual. They do so through a strong emphasis on optimizing people's ability to do their day-to-day activities and educating and empowering people to manage their health conditions, adjust to their situation, and remain active and well *(6,16)*.

The competencies required to deliver interventions for rehabilitation are generally represented within the professions of audiology, clinical psychology, occupational therapy, optometry, prosthetics and orthotics, physiotherapy, and speech and language therapy, as well as by doctors and nurses specialized in rehabilitation medicine. In addition, the rehabilitation workforce often encompasses rehabilitation assistants, technicians and community-based rehabilitation workers, or other health occupational groups delivering rehabilitation interventions. Depending on a person's needs, rehabilitation may be provided by one discipline, although it often requires multi-professional collaboration *(16)*.

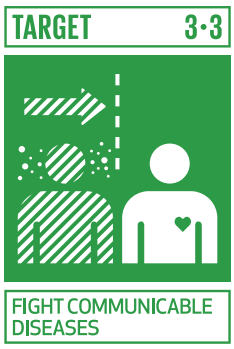
TB occurs globally, but more than two thirds of the global total occur in the so-called *(1)* TB high burden countries. Most of the TB high burden countries have limited capacity to detect, prevent and manage TB-associated impairments. While effective prevention, treatment and rehabilitation approaches to reduce the impact of TB-associated disability exist in these settings, the rehabilitation services are not consistently considered essential and are therefore not adequately funded by governments *(6)*. There is a need to equip health workers to be able to optimize referral between different health services and social protection schemes for the benefit of people with TB and TB-associated disability, in both high burden and low burden countries.

A note on TB among people with disabilities

There is limited data about the incidence of TB among people with disabilities, however, some studies suggest that there is a significantly higher prevalence of TB among people with disabilities *(17,18)*. Several factors place persons with disabilities at higher risk of TB, namely, social exclusion and poverty, which lead to poor education and reduced employment opportunities, resulting in lower standards of living *(3,19)*. Moreover, persons with disabilities may have reduced access to public information about TB and limited or delayed access to diagnosis and treatment, and to social protection services whenever needed *(17)*.

Global conventions and commitments relevant to TB-associated disability

Several global frameworks, conventions, and agreements are in place and can be leveraged to address the needs of people with TB-associated disability. These relate mainly to health and social sectors, with the most relevant ones being those for TB, rehabilitation, universal health coverage, disability, social protection, and mental healthcare.



Sustainable Development Goal 3 (SDG 3) *(20)* calls upon countries to act on health and wellbeing of their people to "ensure healthy lives and promote well-being for all at all ages". Rehabilitation is an essential part of Universal health coverage (UHC) along with the promotion of good health, prevention of disease, treatment and palliative care. SDG 3 also addresses the fight against the TB epidemic and has a specific target (SDG3.3) on ending the epidemic of TB by 2030.

The WHO End TB Strategy *(15,21)* aims to end the TB epidemic by 2030 and provides a blueprint that can be adapted to each Member State's unique situation. The strategy comprises three pillars: integrated patient-centred TB care and prevention; bold polices and supportive systems; and research and innovation. It recognizes the need for government stewardship, coalition building and human rights-based approaches.

THE END TB STRATEGY

Rehabilitation 2030 *(22)* was launched in 2017 by WHO, marking a new strategic direction which recognizes rehabilitation as an essential health service for all, necessary for achieving UHC. To support Rehabilitation 2030, a 'Call for Action' was raised by more than 200 stakeholders, drawing attention to the unmet rehabilitation needs and promoting a health system strengthening approach to efforts in countries. It addresses three main areas, namely the open availability of rehabilitation for all populations, strengthening and integrating rehabilitation into larger health care systems, and acknowledging that rehabilitation is an important service to develop in order to reach universal health coverage.

Intersectoral global action plan on epilepsy and other neurological disorders 2022-2031 *(23)* was adopted by the World Health Assembly in May 2022. The action plan addresses the challenges and gaps in providing care and services for people with epilepsy and other neurological disorders such as tuberculous meningitis and spinal cord TB that exist worldwide and ensure a comprehensive, coordinated response across sectors. Neurological disorders, including those resulting from meningitis, are the leading cause of disability adjusted life years and the second leading cause of death globally *(11,24)*. Despite the high global burden of neurological conditions, access to both services and support for these conditions is insufficient, especially in low- and middle-income countries.

Defeating meningitis by 2030 global road map *(26)* Despite significant progress over the last few decades, meningitis remains a much-feared disease worldwide with a high case fatality rate and a propensity to cause epidemics that present a major challenge for health systems, economies and society. The Defeating meningitis by 2030 global road map has been approved by the Seventy-third session of the World Health Assembly in November 2020 (resolution WHA73.9). The road map sets a comprehensive vision for 2030 "Towards a world free of meningitis", with its third visionary goal being reduction of disability and improvement of quality of life after meningitis due to any cause, including TB meningitis.

The United National Convention on the Rights of Persons with Disabilities *(27)* counts 185 ratifications and 164 signatories. When ratified, governments commit themselves to take action to realize the human rights of all persons with disabilities and to build inclusive legislation, policy, services and communities. Specific articles relate to health care, rehabilitation, assistive products and stigma and discrimination, all relevant for building inclusive, accessible and comprehensive healthcare. Article 26 of the declaration highlights the importance of comprehensive habilitation and rehabilitation services and programmes for people with disabilities, hence also for people with TB-associated disabilities.

Several WHO Resolutions, frameworks and action plans address tuberculosis, primary health care, rehabilitation, mental health, assistive technology, person-centred integrated health care, persons with disabilities, vision care, and hearing care. These resolutions request governments to address specific components of healthcare and typically call for an expansion of services to meet population needs. The WHO Global Report on Health Equity for Persons with Disabilities *(6)* also calls on governments to address unfair conditions, such as stigma and discrimination, low socioeconomic status, poor living conditions and health system barriers, all of which can add to the TB risks faced by this group.

Benefits of comprehensive, integrated, people-centred health care for people with TB-associated disabilities

Typically, TB treatment is one of the most cost-effective of all public health interventions —every US$ 1 invested in TB prevention and care yields a return of around US$ 49 *(19)*, however the assessment of cost-effectiveness may not have accounted for disability *(9)*. Considering similar economic analysis in the WHO Global report on health equity for persons with disabilities *(6)*, factoring in TB-associated disabilities could be expected to contribute further to this return on investment.

Careful analysis of the direct costs (e.g. long-term care and social protection costs) and indirect costs (e.g. exclusion from labour and consumption markets) should be undertaken to make the economic case for more comprehensive, integrated and people-centred TB care.

Moreover, there are many benefits when comprehensive, integrated patient-centred care for people with TB is provided, including:

1. Improved health, functioning and TB treatment outcomes for persons with TB-associated disabilities

Rehabilitation services optimize people's functioning, improving their day-to-day activities and community participation *(6)*. For people with TB-associated impairments or disabilities, rehabilitation commonly improves their mobility, self-care, pain management, respiratory function and mental health. Furthermore, access to rehabilitation and other healthcare services can reduce secondary complications that occur as a result of TB-associated impairments, preventing further impairments and potentially loss of life. Some secondary complications include, for example, non-TB acute exacerbations of lung disease, development of chronic pulmonary aspergillosis and associated haemoptysis, or development of pulmonary hypertension *(3)*. It also contributes to optimizing health outcomes after surgical interventions, such as after surgery for TB.

2. Reduced health system costs

Rehabilitation services can contribute to reduced overall health expenditure by reducing complications and conditions that may require additional health and social protection services *(24,25)*.

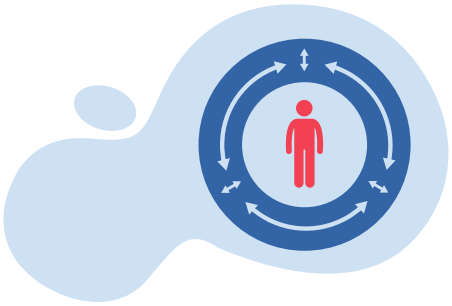
3. Improved societal well-being

Increased social and economic contribution by households and communities has an overall positive impact on society *(3)*. Through better health, functioning and well-being, TB-affected people can more effectively participate in their households and communities, which can also positively impact care costs *(24)*. Additionally, addressing barriers in the community (e.g. stigma or inaccessible infrastructure) enables people to engage in education and work activities and contribute to their communities in a range of ways *(8)*.

Key approaches to improve health and social outcomes for people with TB-associated disabilities

People with TB-associated disability require comprehensive, integrated, people-centred health and social services, which can be realized through well-functioning health and social protection systems.

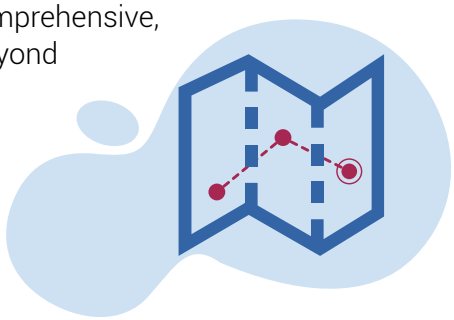
Some of the most critical considerations to address TB-associated disability include the following actions.



1. Establishing comprehensive, integrated people-centred TB care that addresses associated impairments and disabilities, including:

- early identification and screening for impairments, disabilities, and subsequent rehabilitation needs, including follow-up and case management of at-risk populations during and after TB treatment;
- effective, and timely referral mechanisms for rehabilitation and mental health services;
- up-to-date clinical guidance for integrated patient-centred care for people with TB-associated impairments and disabilities, in line with WHO consolidated guidelines for TB, and particularly strengthening early access to quality diagnosis, treatment and care, including monitoring and management of adverse/side effects of anti-TB medicines, especially for persons with existing co-morbidities or under treatment for drug-resistant tuberculosis;
- provision of coordinated, multi-disciplinary care that includes rehabilitation, mental health care or other necessary healthcare for people with TB-associated disabilities, especially those with complex needs;
- coordination and linkages with disease programmes responsible for TB comorbidities to enhance rehabilitation services that meet individual patients' needs, based on the WHO Framework for collaborative action on tuberculosis and comorbidities; and
- coordination and linkages between health care providers and social protection services to address the health care, financial and social security needs of people with TB-associated disabilities.

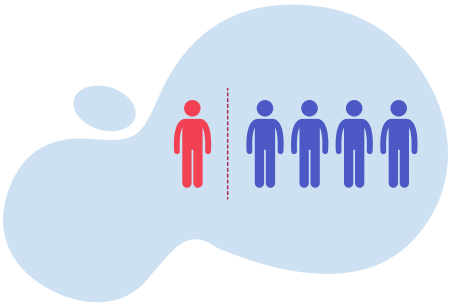
2. Ensuring effective planning across health systems, such as:



- planning of services for people affected by TB that ensure comprehensive, integrated, people-centred care along a continuum, including beyond completion of TB treatment;
- ensuring that rehabilitation services are part of national health planning and have adequate funding, improving their availability and affordability for people with TB-associated disabilities;
- strengthening the rehabilitation workforce and quality of rehabilitation services, as well as building rehabilitation competencies among health workers engaged in the delivery of care for people with TB and post-TB disease; and
- appropriate planning for the cost of addressing the needs of people with disability, such as accessible health facilities, health information in appropriate formats, assistive products,2 personal assistance or accessible transportation.

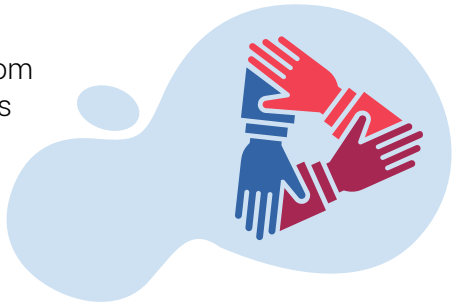
2 *Assistive technology* is an umbrella term covering the systems and services related to the delivery of assistive products and services. *Assistive products* maintain or improve an individual's functioning and independence, thereby promoting their well-being. Hearing aids, wheelchairs, communication aids, spectacles, prostheses, pill organizers and memory aids are all examples of assistive products (https://www.who.int/news-room/fact-sheets/detail/assistive-technology).

3. Addressing stigma and discrimination towards people with TB and related disabilities, through:



- raising awareness in local communities regarding TB and its long-term consequences including associated impairments and disabilities;
- ensuring information is available to communities in accessible and appropriate formats and that it reaches persons with disability in at-risk groups, such as those with poor living conditions and/or living in congregate settings, as well as their immediate social networks; and
- ensuring health workers caring for people with TB are inclusive and welcoming of people with TB-associated impairments and disabilities and encourage them to partake in community life.

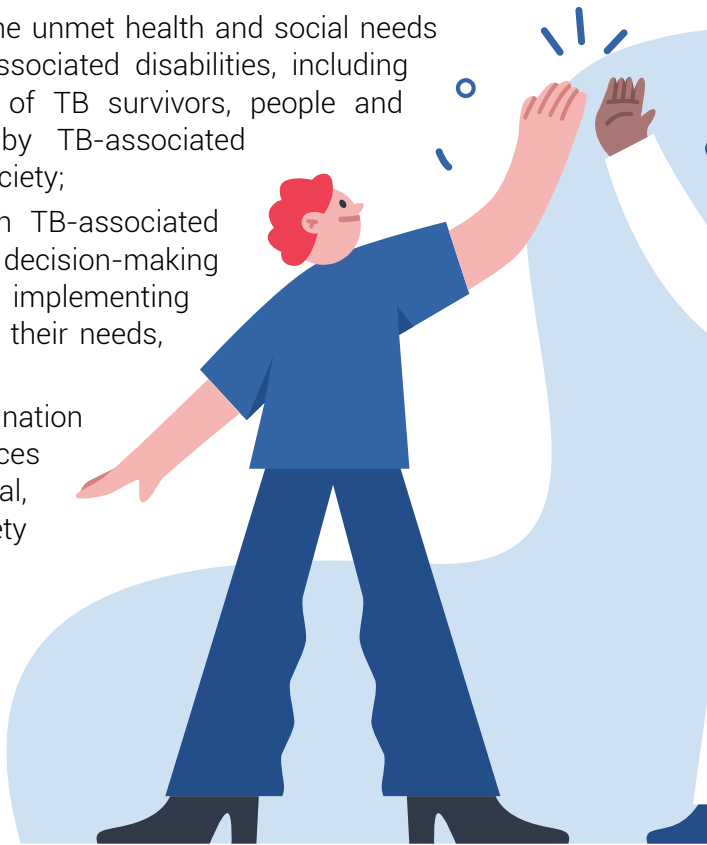
4. Improving collaboration with social support and social protection services by:



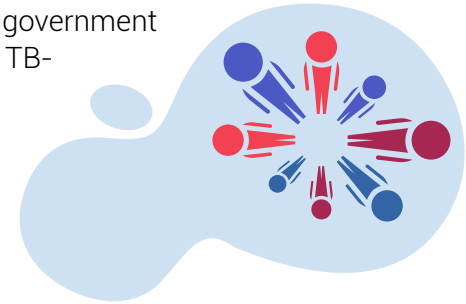
- engaging people with TB-associated disabilities, who may benefit from a range of services that extend beyond healthcare, such as services that support social inclusion, legal protection, access to education and social protection benefits; and
- promoting multisectoral and multistakeholder collaboration in the designing, planning and implementation of services for people affected by TB and TB-associated disabilities, such as regular collaboration between health and social services.

5. Expanding social awareness of the needs of people with TB-associated disabilities through:

- drawing attention to the unmet health and social needs of people with TB-associated disabilities, including through the voices of TB survivors, people and families impacted by TB-associated disability, and civil society;
- engaging people with TB-associated disabilities in the decision-making process for designing and implementing policies, programmes and services to address their needs, reduce barriers and eliminate discrimination; and
- fostering opportunities for regular collaboration and coordination among stakeholders involved in the provision of services for TB, rehabilitation and disability, at the local, national, regional, and global levels, including among civil society organizations.



6. Promoting multisectoral collaboration via:



- strengthening multisectoral cooperation and action, including across government sectors and UN agencies, in order to address the needs of people with TB-associated disabilities in a comprehensive and sustainable manner;
- reinforcing multisectoral approaches to tackle TB-associated disability through mechanisms such as the Health in all Policies (HiAP) and the Multisectoral Accountability Framework for TB (MAF-TB); and
- fostering coordination and collaboration on TB-associated disability and rehabilitation among civil society organizations, development partners and donors to catalyse investments.

7. Generating information and evidence by:

- collecting adequate data and information to enhance the understanding of the needs of people with TB-associated disabilities and, accordingly, to support effective decision-making and service planning for people with TB-associated disabilities; and
- developing a well-funded research agenda to further insights into TB-associated disability, particularly regarding linkages between TB, impairments and disabilities and how they may change over time; the demographic, clinical and socioeconomic determinants of TB-associated disabilities; links between stigma, discrimination and TB-associated disability; the extent and distribution of TB-associated disability; and the impact of specific interventions, among other evidence needed to inform policy updates and guidelines development.

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