

### Thematic Brief

## IMPROVING THE HEALTH AND WELLBEING OF PEOPLE LIVING WITH NEGLECTED TROPICAL DISEASES THROUGH REHABILITATION AND ASSISTIVE TECHNOLOGY



Photo credit: The Leprosy Mission India





Improving the health and wellbeing of people living with neglected tropical diseases through rehabilitation and assistive technology: thematic brief

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#### **Key messages**

- Neglected tropical diseases (NTDs) affect more than one billion people worldwide, including children, and young women and men in their prime working age.
- NTDs are intimately linked to poverty and affect some of the world's most marginalized communities, predominantly in Africa, Asia and the Americas.
- If not diagnosed and treated early, many NTDs can lead to long-term disability, mental health conditions and stigmatization; examples of such NTDs include Buruli ulcer, cutaneous leishmaniasis, leprosy, lymphatic filariasis, mycetoma, onchocerciasis, snakebite envenoming and trachoma.
- Rehabilitation and assistive technology are essential health services and required to achieve Universal Health
  Coverage. They improve the health, well-being, everyday functioning and societal participation of persons
  living with NTDs. However, most people with NTDs in need of rehabilitation and assistive technology do not
  have access to them.
- Access to rehabilitation and assistive technology is underpinned by its availability at all levels of healthcare and health workers having the necessary competence, guidance and resources to deliver this care. In many NTD endemic countries, there are significant service gaps that need to be addressed, particularly at the primary healthcare and community level.
- Adopting a comprehensive and integrated approach to NTDs care that includes the provision of rehabilitation
  and assistive technology, engaging with people living with NTDs, and building partnerships and collaboration
  across various sectors is key to ensuring persons living with NTDs live healthy, productive and dignified lives.

## 1. RECOGNIZING THE ISSUE - THE UNMET REHABILITATION AND ASSISTIVE TECHNOLOGY NEEDS OF PEOPLE WITH NEGLECTED TROPICAL DISEASES

### **Unmet need and gaps**

Neglected tropical diseases (NTDs) are a diverse group of diseases that affect more than one billion people worldwide. Causes of NTDs include viruses, bacteria, protozoa, helminths and ectoparasites. NTDs mainly affect children, young women and men in their prime working years, living in vulnerable and marginalized communities in tropical and subtropical countries. Poor water, sanitation and hygiene; limited food safety; close interactions with domestic animals, livestock and wildlife; and lack of awareness represent common determinants of NTDs.

NTDs can be effectively prevented and treated with cross-sectoral public health interventions (e.g. vaccination of animals, access to safe water), affordable medicines and cost-effective programmes promoting early detection, diagnosis and management. However, if not diagnosed and treated early, many NTDs lead to long-term disability, including mental health conditions and stigmatization. Many people with NTDs can benefit from rehabilitation and assistive technology, these promote their health and well-being and enable them to live more productive, independent and dignified lives.

### **Consequences of unmet need**

Many countries with endemic NTDs also have limited rehabilitation and assistive technology services. Consequently, people with NTDs commonly experience significant unmet need for rehabilitation and assistive products. In addition, as NTDs affect some of the poorest communities in the

world, rehabilitation and assistive products, when available, are often provided by charities or by private businesses and in many cases are unaffordable.

Unmet rehabilitation and assistive technology needs can have health, social and economic impacts to the person and their community.

**Health impacts include** deterioration in a person's health, including development of additional comorbidities and complications, increased requirement for healthcare such as readmission to hospital, and worsening of health outcomes.

**Social impacts include** the difficulties experienced by individuals, such as difficulties moving around and caring for themselves and their family. They also include the suffering experienced from stigma. While an NTD alone may result in stigma, when combined with disability, stigma is amplified and often leads to greater discrimination and social exclusion. Subsequently, people with disability from NTDs often have less education and economic opportunity. This feeds into a vicious cycle of poverty which impacts on the individual, their family and community.

**Economic impacts include** the direct and indirect costs that are related to the cost of healthcare and loss of income associated with reduced productivity. The unmet health needs (including rehabilitation and assistive products) of people with NTDs is estimated to cost developing communities billions of dollars each year. Trachoma, a common NTD affecting the eyes, for example, is responsible for blindness or visual impairment for nearly 2 million people and the annual economic value in terms of lost productivity is estimated at USD 2.9–8.0 billion annually.

Rehabilitation is a set of interventions needed when a person is experiencing or likely to experience limitations in everyday functions due to ageing or a health condition, including chronic diseases or disorders, injuries or traumas. Examples of limitations in functioning are difficulties in thinking, seeing, hearing, communicating, moving around, having relationships or keeping a job. It includes a broad range of interventions, including education and advice, therapeutic exercise and training, utilization of modalities (e.g. thermal energy), assistive product provision, and individual adaptations to the home or work environment. For people with NTDs, rehabilitation commonly addresses mobility, vision, self-care, activities of daily living and emotional functions.

Assistive technology is the application of organized knowledge and skills related to assistive products, including the systems and services necessary for procurement and provision of assistive products. There are many types of assistive products which support mobility, vision, hearing, cognition, self-care and communication. For people with NTDs, commonly-required assistive products include therapeutic footwear, wheelchairs, crutches, prosthetics, orthotics (splints), eyeglasses, white canes, and toilet and shower chairs.



Photo credit: Abanda

### The impact of unmet need: Rosalie's story

Rosalie lives in Akam Engali, a village in the Centre Region of Cameroon. When still young, she had Buruli ulcer and was treated by a traditional healer. However, the wound re-opened and she underwent a left lower limb amputation four years ago.

Since the amputation, Rosalie has been unable to work in her farm or carry water alone from the well; a helper has been supporting her in getting the supplies she needs to perform her daily activities. Now she runs a small business at home, making doughnuts and tobacco powder.

Rosalie uses old crutches that she inherited from her late husband, who died recently. The husband had an amputation too, and was provided with crutches seven years ago. She never directly benefited from rehabilitation and AT services, and learned alone how to use the crutches. She couldn't acquire her own prosthesis because of the high cost.

Rosalie is well integrated in the community and the crutches help her to move from one place to another in her house and in the village; however, without prosthesis her mobility remains very limited. Rosalie dreams of having a motorbike that could help her to move more. Rosalie suggests that rehabilitation and AT services should be more available and accessible for those with limited finances.

# 2. WHY COUNTRIES SHOULD ACT - THE LIFE-CHANGING POTENTIAL OF REHABILITATION AND ASSISTIVE TECHNOLOGY FOR PEOPLE WITH NTDs

Access to rehabilitation and assistive technology is life- changing. It can enable people to care for themselves, communicate, be more physically mobile, go to school or be more economically productive. Rehabilitation and assistive technology for people living with NTDs can achieve this, and more. They also prevent secondary health complications and reduce the need for further hospital admission. Additionally, they reduce the need for formal support services, long-term care and personal assistance. Rehabilitation and assistive technology improve the overall quality of people's lives by enabling them to be more independent, participate in society, and reduce the experience of disability.

Rehabilitation and assistive technology are essential components of healthcare that are necessary for achieving Universal Health Coverage (UHC) and uphold peoples' dignity, rights and enjoyment in life.

### The benefit of rehabilitation and AT: Admar Masseis' story

Admar Masseis lives in Brazil with his wife and stepdaughter. He has leprosy and, to protect his feet, he uses orthopedic footwear with adapted insoles. With the use of shoes, he feels more stable when walking, and can perform several activities such as sweeping the house, cooking, changing the gas, going out to socialize, going to the bank to pay bills, cycling and fishing.

The orthopedic footwear, the insoles and rehabilitation services greatly improved Admar Masseis' quality of life. Previously he wore slippers, which hurt and resulted in frequent ankle strains. He hopes that, in the future, the rehabilitation services he needs will be closer to his home, as he still needs to travel to a bigger city to get the care he needs.

### **Global agreements and frameworks**

Global frameworks exist that recognize the comprehensive needs of people at risk of or living with NTDs as well as the need for strengthening health systems for rehabilitation and assistive technology.

### Ending the neglect to attain the sustainabled development goals: A road map for NTDs 2021–2030

The road map for neglected tropical diseases 2021–2030 sets out global targets for 2030 and milestones to prevent, control, eliminate and eradicate a diverse set of 20 neglected diseases and disease groups. One target is that by 2030, 90% of countries will have guidelines for management of NTD-related disabilities within national health systems. The road map also describes the integrated approaches needed to achieve these targets through crosscutting approaches such as rehabilitation and assistive technology.

## Global cooperation on assistive technology (GATE)

The GATE initiative was established in 2014 with the goal to improve access to assistive technology globally. To achieve this goal, the GATE initiative is focusing on five interlinked strategic areas: the development of people-centered AT policies and programmes, selection and procurement of quality, affordable assistive products, health personnel training and capacity building, and integrated provision. In 2018, delegates at the World Health Assembly adopted a resolution on assistive technology, committing to develop policies and programmes to accelerate access.

Read about the GATE initiative.

#### Rehabilitation2030

In February 2017, the Rehabilitation2030 initiative was launched, marking a new strategic direction which recognizes rehabilitation as a health service for all, and essential for achieving UHC. To support the Rehabilitation2030 initiative, a 'Call for Action' was raised, drawing attention on the need to strengthen the health system to provide rehabilitation and calls on stakeholders to integrate rehabilitation into all levels of healthcare.

Read about Rehabilitation 2030.

### Rehabilitation and assistive technology for people with NTDs

UHC means that all people should be able to access the health care they need, including rehabilitation and assistive technology, without facing financial hardship. This includes people who have NTDs. Access to healthcare necessitates the availability of rehabilitation and provision of assistive products at all levels of healthcare, from tertiary through to primary healthcare. This type of care should also be available across different service delivery platforms, such as high-intensity, longer-stay rehabilitation units, or community settings, for example someone's home. Rehabilitation and assistive technology are required during the acute, sub-acute and chronic phases of the health condition and should be delivered along a continuum in a timely manner. Designing appropriate, affordable, accessible and person-centered services is essential to produce optimal health and functioning outcomes for people with NTDs.

Over time, an NTD can impact on the structure and function of a person's body resulting in difficulties completing everyday activities. Consequently, different types of rehabilitation and assistive products are required to improve a person's functioning, and to reduce the risk of further complications. Table 1 includes common NTDs and the types of rehabilitation and assistive products people may benefit from; in addition to these, the following are also relevant to many people with an NTD: education and training for selfcare and activities of daily living; hygiene and self-management (e.g. use of toilet and shower chairs); mental health support and counselling; and home modifications.

Table 1. Different types of rehabilitation and assistive technology commonly required for people with NTDs

NTD	Types of impairments and functioning difficulties	Type of rehabilitation and assistive products
Buruli ulcer	Skin ulcers and scars, leading to severe contractures and difficulty in moving arms and legs. Loss of deep tissue. Radical surgery, including amputation, might be needed in some cases	Exercises and techniques, including use of compression garments, to maintain movement, prevent contractures and reduce swelling
		<ul> <li>Provision of walking aids, orthotics, wheelchairs and products for self-care</li> </ul>
Cutaneous leishmaniasis	Skin ulcers and scars, leading to contractures and difficulty in performing movements	Exercises and techniques to maintain movement, prevent contractures and reduce swelling
		<ul> <li>Provision of walking aids, orthotics, wheelchairs and products for self-care</li> </ul>
Leprosy	Loss of sensation in the skin, including hands, feet and eyes, which can gradually lead to	Exercises to address loss of sensation, prevent contractures and maintain mobility
	difficulty in walking, difficulty in using hands	. Evo care to provent blindness

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