

SHORT REPORT

## Remote disability and leprosy services via basic communications technology

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**Summary** This short report describes the rationale for and process of developing and refining a manual to assist professionals, workers, families, volunteers, and people with disabilities in low- and middle-income countries (LMIC), to make better use of appropriate and accessible communications technology. The manual is intended as a basic step towards enhancing disability and leprosy services where they are not accessible and/or affordable to people in remote areas of LMIC.

A semi-formal process comprising several layers of feedback and review, and subsequent preliminary evaluation was encouraging. It suggests that the pilot version warrants further implementation as well as more formal research to rigorously evaluate the effectiveness and to refine the content of the manual.

**Keywords:** Disability services, leprosy services, communications technology, volunteers, intermediate level workers

### Rationale

In Myanmar, the obstacles and complexity of providing leprosy and disability services through the COVID pandemic and successive lockdowns were greatly amplified by a military coup and state of emergency restrictions. Initially nearly all leprosy and disability services in the country were ceased, but as the need for services increased, a few providers attempted

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A manual to enhance the use of appropriate and accessible communications technology to help professionals, workers, families, volunteers, and people with disabilities in low- and middle-income countries.

different approaches, but with limited success. Some agencies tried to deliver services using technologies and devices that were unavailable or inaccessible to the majority of people with disabilities and families. Others tried to use technologies that were too limited to support the tasks they were trying to achieve.

With funding from NOREC (<https://www.norec.no/en/>), The Leprosy Mission Myanmar undertook an initiative to explore the viability of fostering alternative approaches to conventional, face to face therapy and supports using appropriate technology. Based on initial explorations for that initiative, it was noted that:

- The situation for people with disabilities/leprosy and their families beyond the major cities, and particularly in remote areas, was extremely difficult.
- While most people with disabilities in remote and inaccessible areas had assistance from family members, they typically lacked skills to provide the required services.
- While there is a network of community health workers in the country, most lack knowledge and skills regarding the needs of people with disability and leprosy.
- Likewise, while there are a number of therapists, welfare workers and other health professionals in the country, they also typically do not have disability- and leprosy-specific skills to provide adequate services.

### **Precedent**

The use of technology to support and enhance disability and leprosy services in Low- and Middle-Income Countries (LMIC) is an important and rapidly growing area of focus. For example, there are high quality contemporary Apps for diagnosing leprosy and skin conditions (<https://nlrinternational.org/what-we-do/projects/skinapp/>), and to guide rehabilitation interventions for people with leprosy and a number of disabling conditions (<https://enablement.eu/rehapp>). Likewise, beyond individual interventions, the use of appropriate mobile technology to support and enhance disability and leprosy services is also established.<sup>1</sup> In LMIC, telehealth is increasingly identified as a potential support mechanism for intermediate level workers in rehabilitation and disability services,<sup>2</sup> and to support personal care in the home.<sup>3</sup> Indications are that telehealth approaches are beneficial to support Community Based Rehabilitation (CBR) workers who assist vulnerable and marginalized populations,<sup>2</sup> and when used consistently to guide workers, can improve outcomes for people with disabilities.<sup>3</sup>

### **Development of the manual**

While this emerging focus and these promising results are encouraging, it was evident from current research,<sup>2,3</sup> and from our informal explorations in Myanmar, that there was a need for greater clarity regarding the following:

- Which communication technologies are best suited for people in LMIC?
- Which types of rehabilitation and disability service are most conducive to being provided via communication technologies?
- Which service users would draw most benefit from this approach?
- In what context (existing services, volunteer supports, family resources, etc)?
- How should the respective technologies be used?

These questions underpinned the fundamental motivation for the development of a manual. The primary goal of the manual then, was to assist local professionals, workers, families,

volunteers and people with disabilities in Myanmar (as well as in other LMIC), to better use appropriate and accessible remote technologies for service provision.

In pursuit of this goal, the TLMM team conducted a number of explorations of potential ways to support services, and potential content of such services. Team members held discussions with colleagues and clients regarding:

- The nature of mobile phones and devices available to the families and communities of people with disabilities in remote areas.
- The quality, bandwidth, cost and availability of internet access for the families and communities of people with disabilities.

Team members also held discussions with colleagues regarding:

- The most common rehabilitation and disability services they provide to people with disabilities/leprosy in rural and remote communities.
- The rehabilitation and disability services they think would be most amenable to adaptation via remote technology type delivery (including mediated delivery via volunteer, family member or intermediate level worker).

### **First revision**

In response, a draft version of a manual was devised addressing a number of core areas of rehabilitation, disability, and leprosy care and support, which could be delivered and supported by professionals and experienced staff and mediated by family members, community workers, intermediate level staff, and volunteers.

After completion of this draft, a copy was sent to all of the TLMM staff working with people with disability/leprosy. It was refined based on their feedback. A revised version was then developed.

### **Second revision**

This revised version was distributed more broadly for detailed critique, editing and more specific feedback. Three key sources were utilized:

- local NGOs in Myanmar (two local teams of qualified and experienced therapists working for international NGOs),
- sister organisations internationally (key staff of TLM Nepal and TLM Bangladesh), and
- international experts (highly experienced expert physical therapist and occupation therapist working internationally within the disability/leprosy sector).

Each expert/expert team was provided with the revised version of the manual and asked to read the manual and comment on the accuracy, relevance, suitability, completeness, and presentation of the information for a LMIC context. They were provided with a formatted version of the manual that requested them to provide:

- high level conceptual feedback on the major aspects of the manual and the intended approach, and
- specific detail about the information on each page of the manual.

Each of the experts/expert teams went through the manual in detail and provided feedback at the two levels noted. They entered their comments directly onto the relevant section or page

of the manual and returned a completed version. All of the feedback was then collated into a single copy. The five team members (Ms Zin Mar Theint, Ms Khin Mar Swe, Mr Zin Lynn Htun, Dr Kathy Kuipers and Dr Pim Kuipers) went through each entry on the full feedback version and either:

- made major and minor changes accordingly,
- reworded sections,
- added requested information or resources,
- amended graphics and formatting, or
- (where there were contradictory comments), sought to amend where possible, or chose not to make changes, or
- (where there were major changes suggested that were out of scope of the current project), identified these issues as potential changes for subsequent versions.

The final edited version was checked for consistency and then released as the official pilot version. The pilot version covered:

Introduction: Addressing the challenge of the best use of technology for providing remote leprosy and disability services?

Chapter 1: Providing therapy to people with disabilities using remote technologies (including guidance on screening, assessment and problem identification, goal setting and intervention planning, conducting interventions, and monitoring and follow-up).

Chapter 2: Assisting with mobility devices (including assessment, problem identification and intervention planning, and monitoring and follow-up).

Chapter 3: Assisting with home adaptation (including assessment and barrier identification, implementation, and follow-up).

Chapter 4: Providing health education for prevention of disabilities (including health education for prevention of disabilities).

Chapter 5: Services for people affected by leprosy (including ulcer prevention and care, increasing awareness, wound management and follow-up).

Chapter 6: Providing referral to other health or disability services.

Chapter 7: Conducting training activities (including providing training to community volunteers, providing training to NGO and GO staff and professionals, and providing training to church and community groups).

Chapter 8: Providing information and training for mainstream organisations (including providing training regarding leprosy and care, and providing training on disability and disability inclusion).

Chapter 9: Providing information for the whole community (including information on leprosy awareness and knowledge, leprosy related stigma, and general disability awareness).

### **Evaluation of the pilot version**

A translated version (Myanmar language) of the pilot remote service provision manual was trialled by the TLM Myanmar team from January to December 2021 through an initiative using 20 volunteers across 15 local churches. Volunteers were supported by three TLMM professional staff (physical therapists and rehabilitation staff) to use the manual (in hard copy as well as an electronic version where required) in providing support and services to 291 persons with disability and leprosy. Communication with these people occurred via phone call, text message, “Viber” group messages and occasional video calls. In November 2021, a sample of

**Table 1.** Key survey items

Helpfulness of services delivered this way				
Very helpful 33%	A little helpful 20%	OK 47%	Not really helpful 0	Not at all helpful 0
Satisfaction with services delivered this way				
Very satisfied 59%	Mostly satisfied 33%	It was OK 8%	Not really satisfied 0	Not at all satisfied 0
Likely to recommend such services to others				
Yes definitely 13%	Probably 15%	Not sure 69%	Probably not 3%	Wouldn't rec'mnd 0

61 people with disability and family members was briefly surveyed regarding their experience of remote service provision in this manner.

Key points from the informal survey (Table 1) indicate that over 50% found services delivered this way to be helpful, and nearly 90% of respondents were generally satisfied with remote services and this mode of service delivery, however, many were unsure about recommending such services to others. It was concluded that despite the limitations of the manual and the remote, volunteer-based approach, and a preference for face-to-face services, the majority of people were accepting and relatively satisfied with the approach.

In response to open ended questions about the technology-based approach and services, most noted that they appreciated the convenience and the ease of communication, many seeing it as the best communication channel during the COVID and coup situation. As was expected, technical issues were a key factor, with comments about being restricted to the phone, no video contact, poor internet connectivity, poor phone signal and misunderstandings (but encouragingly, one third of respondents reported no technical difficulty).

When asked about possible advantages of such an approach, the majority noted aspects such as increased contact with supports, having a means of communication, and better use of time. Only one person described rehabilitation outcomes as an advantage. Over one third said there were no advantages to this approach.

In summary the people who received remote services via the technology-based approach, guided by the manual and church volunteer support, rated the process and outcomes surprisingly positively, given that these services are mostly intended as a substitute for face-to-face services where they are unavailable or unaffordable.

## Discussion/conclusions

The development of the described manual (which can be accessed at <https://www.leprosy-information.org/resource/introductory-manual-remote-service-provision-supporting-people-disability-and-leprosy>) has been an attempt to address the pressing need for additional training and support for family members, people with disability, volunteers, professionals, and particularly CBR workers<sup>2</sup> in LMIC. Current research suggests that in these settings, appropriate communication technology (which this manual seeks to support) can be used to: facilitate caregiver training,<sup>3</sup> support CBR workers,<sup>2</sup> build the individual person's competencies, performance, capacity and participation,<sup>3</sup> and even address inequitable access to quality health care.<sup>2</sup>

The people who received remote services via the pilot manual and church volunteer support rated the process and outcomes surprisingly positive, given that these services are intended as a substitute or replacement for face-to-face services where they are unavailable or unaffordable. It was concluded that this is a suitable foundation for further expansion and refinement of the manual and these approaches. There is great potential to “scale up” such services, especially for people in remote areas, people isolated by restrictions, and others who may not be able to attend (or afford) face to face services.

The manual is a small step in the process of making rehabilitation, disability and leprosy services more accessible and affordable to people in remote areas of LMIC. The encouraging feedback from reviewers and preliminary evaluation results, suggest that further implementation is warranted. More formal research to rigorously evaluate the effectiveness and refine the content of the manual will enhance the use of appropriate technology in volunteer/intermediate worker mediated disability and leprosy services.

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### **Conflict of interest**

The authors declare that they do not have any conflict of interests.

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