

Zero Leprosy Best Practices

Best Practice: *Reduction of Stigma through Community-Based Inclusive Development (CBID) Practices, Nepal*

Subthemes

- Reduction of stigma, discrimination, and exclusion

Target Audience(s)

- Policy leaders
- Program managers
- Trainers
- Health staff
- Persons affected by leprosy
- Scientists
- Donors
- Other partners such as NTD NGOs

Contributors

C Sharma, The Leprosy Mission Nepal

Key Messages

1. Leprosy causes stigmatization, a social issue; medical treatment is not enough.
2. Socioeconomic condition is a major factor in perpetuating stigma in communities; hence, a model that can transform the socioeconomic condition of people affected by leprosy is pivotal.
3. Stigmatization leads to discrimination and mental health problems and should be addressed with priority.
4. Wider community involvement and engagement with persons affected by leprosy is necessary to dispel myths and encourage mutuality among affected and non-affected members of a community.

Key Informant / Date Submitted

C Sharma, The Leprosy Mission Nepal
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Description of the Best Practice

Introduction

The Leprosy Mission (TLM) was invited by the King of Nepal to start leprosy control work in Nepal in 1957. TLM asked the government for a piece of land to establish a hospital and was given barren land in the southern part of Lalitpur that was used as a graveyard by the area's tribal people and was not visible

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from the Kathmandu valley or from the sacred Pashupatinath temple. Since the establishment of Anandaban Hospital, TLM has been actively involved in leprosy control work in partnership with the government of Nepal and communities across the country. Although people used to throw stones whenever the hospital vehicle passed the village and community, the situation has immensely changed. However, despite advancements and widespread leprosy awareness, leprosy stigma continues to haunt people's minds and hearts. We continue to hear stories of segregation and discrimination in the communities, and people turn up late for treatment because of the fear of possible stigmatization. Stigma and lack of knowledge about the disease has contributed to late case presentation and disability. Disability causes further marginalization and less opportunity for employment and ultimately leads to an impoverished state with reduced income and social standing.

At the beginning, TLM was mainly medically focused on leprosy control work through Anandaban Hospital and its clinics in different parts of the country. The mission later realized that leprosy is not merely a medical problem but also a psychosocial and economic problem. TLM began taking a holistic approach to this problem through community-based rehabilitation (CBR) work. As stigma is one of the main barriers to eliminating leprosy, TLM Nepal began helping some severely affected individuals integrate back into their communities by providing small-scale grants for businesses and scholarships for leprosy-affected individuals and their children connected with rehabilitation centres and sometimes to the Khokana leprosarium. While these activities were very useful for people affected by leprosy who were marginalized in their communities, this was primarily a vertical approach without engagement of the community members. There was a need for integration of people affected by leprosy into the communities as respected members and contributors. Although the grants and individual support to people affected by leprosy were helpful, their purpose is not complete unless the people affected by leprosy are integrated as important community members (as in the Bible story where people affected by leprosy were sent to the priest by Jesus for verification and acceptance in the community).

To mainstream people affected by leprosy in the communities, TLM Nepal started its very first CBR project, Community Active Participation (CAP), in Bara, one of the highly endemic districts of Nepal. For this project, people affected by leprosy, people with disabilities, and other marginalized groups participated to form self-care/self-help groups. These groups were formed on business models that encouraged regular savings and other micro-credit activities among the group members. There were also various other important components that focused on prevention of disability among people affected by leprosy by regularly practicing self-care. This was considered part of the group activity to promote physical, psychological, and social well-being of the participating members. The aim of this first CBR project was to build the capacity of people affected by leprosy, people with disabilities, and marginalized groups in different areas and then to encourage self-sustainability of these groups after forming cooperatives that have access to government resources. Since the implementation of the first CBR project, TLM Nepal has made advancements and gained wide experience in the area of CBR, with more attention given to disability and inclusion. TLM Nepal's CBR activities now include over 51 cooperatives, 101 self-help groups, and over 10,000 members from 23 districts. Among the cooperative and group members, 48% are female and approximately 20% are individuals living with disabilities.

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Problem(s) to be addressed

TLM Nepal's former model was based on medical support/welfare of the individual. It did not address the holistic needs of people affected by leprosy and was unable to integrate them into their communities. Therefore, a new model, formerly based on five components of CBR, was revised and renamed community-based inclusive development (CBID).

People affected by leprosy came primarily from impoverished areas and living conditions. Research shows that leprosy is synonymous with poverty and that the voices of affected individuals are rarely given importance in community activities or social functions. Several studies suggest that persons with higher income have higher influence and respect in the community than those with lesser income or social status. People affected by leprosy, given their condition of disability and anesthetic hands and feet, have limited ways of earning a living. They lack access to financial services and resources and are therefore unable to gain financial freedom. Examples of problems to be addressed by the model include

- Stigmatization from community and family members
- Self-stigma as a psychosocial challenge due to internalizing the public's attitudes toward them
- Lack of opportunities for income generation
- Lack of self-care practice at home, which enhances disability
- Inadequate education in wash, sanitation, and hygiene practices
- Lack of a unified effort and voice to change the image and conditions of people affected by leprosy
- Lack of community and family support to uplift people affected by leprosy

Impact on the population

- Deterioration of physical and mental health and progressive disability, leading to minimized job opportunities and thereby impacting personal income
- Poor (and lack of healthy) sanitation practices that restrict the ability of people affected by leprosy to practice healthy self-care, which is required for good health and prevention of disability
- Noncompliance to medicines (multidrug therapy [MDT] completion rate is poor), which might lead to an increased risk to the wider population of contracting the disease
- Further stigmatization and discrimination, leading to isolation from community and family members. Those who experienced deep stigma became substance and alcohol dependent. Approximately 50% of people affected by leprosy develop mental health issues, causing further marginalization from the mainstreams of the society.

If not directly a leprosy practice, what is the relevance for leprosy control?

Self-help group (SHG) members are trained in identifying cases and making referrals to appropriate leprosy diagnostic centers. Case reporting from the projects are mentioned elsewhere in this document. The groups also support and organize skin camps that can help find new cases and encourage self-care practices that help prevent disability. For example, there have been 12 suspected and confirmed

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leprosy cases reported by SHG members from the Livelihood and Income Generation project, 11 reported from PACED SHG members, and 50 from CEDAR SHG members. As peer supporters, the members also encourage each other to continue taking MDT, which can improve treatment compliance.

Which objectives were achieved?

- Increased participation (decrease in participation restriction scale as a proxy indicator to measure stigma) in the PACED, CEDAR, and LIVE projects
- Improved WASH practices leading to improved health, improved self-care practices, and less stigma (e.g., from an unhygienic environment)
- Improved economic wellbeing as a result of the business model intervention to enhance economic activities
- Improved self-advocacy and leadership and access to government services and facilities
- Recognition of these groups by different institutions
- Improved mobility

Objectives and Methodology

The main objective of the projects was to mainstream people affected by leprosy into the communities. The primary assumption is that people are further marginalized and experience disability conditions once they are identified as people affected by leprosy in the communities. Other objectives that support the above main objective include

- Improve the quality of life of people affected by leprosy through various social interventions and tools
- Increase social inclusion of people affected by leprosy by involving people with disabilities and marginalized groups
- Increase household income of people affected by leprosy through community-based, micro-credit activities
- Improve health and reduce activity limitations of people affected by leprosy through self-care and basic health-related activities like WASH
- Improve the image of people affected by leprosy and others marginalized in the communities by building their capacity in advocacy and community outreach activities, hence reducing stigma and discrimination
- Develop community-based and -owned social institutions to carry on sustainable and inclusive financial and psychosocial activities

Methodology used

CBR, now called the CBID project, is launched after a situational analysis is done by collecting leprosy data and other relevant indicators related to poverty, health, and social contexts. This is followed by participatory rural appraisal, which is a participatory approach to identify as well as prioritize community needs. The steps followed include:

- Participatory Rural Appraisal (social mapping included) in the endemic areas

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- Baseline survey to identify people affected by leprosy and other marginalized groups
- Forming SHGs with people affected by leprosy, people with other disabilities, and other groups who have experienced marginalization caused by their different social condition
- Support of assistive devices and physio and occupational therapy services
- Building capacity in leadership, raising awareness in leprosy, and promoting advocacy, self-care, WASH, income generation, micro-financing, and business cases development for resource tapping, etc.
- Linking the groups with different government line agencies and other agencies working on different thematic sectors
- Regular monitoring of the progress and undertaking baseline, midline, and end-line surveys
- As in other projects, the project passes through five stages of management: situation analysis (Stage 1), planning and design (Stage 2), implementation and monitoring (Stage 3), evaluation (Stage 4), and learning and sharing (Stage 5)

Was the design based on evidence?

CBR is a well-established [model](#) that focuses on five components and five associated elements to address disability issues in communities. Since the development of the CBR model, the need in the community has continued and the vertical way of operation has been shown to no longer be effective. Therefore, the CBR model has been updated to be a more inclusive model and is now called the CBID model. Disability and other agendas have been viewed through the lens of development rather than just as a project or program at a point of time.

TLM Nepal earlier used the CBR model to address the leprosy issue in the community, especially as a community level intervention to reduce stigma and discrimination caused by different socioeconomic factors. However, now, the CBID model is implemented throughout its community-based projects, which involve a wide range of activities and intervention to bring long lasting change in the lives of people affected by leprosy.

Implementation of Practice

Main activities

- Participatory rural appraisal
- Baseline survey
- Formation of self-help groups
- Monthly meeting of the members
- Income generation training and sensitization
- Education on leprosy and mental health implications
- Business plan development
- Organization development
- Community need assessment training

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- Radio program to raise awareness of leprosy
- Distribution of information, education, and communication (IEC) materials
- Training on WASH
- Interaction with community members
- Linking with other stakeholders and relevant CSOs
- Disability Day/Leprosy Day celebration
- Community outreach and development
- Skin camps
- Advocacy
- Distribution of assistive devices
- Regular monitoring
- Timely evaluations followed by recommendation
- Dissemination of evidences as part of accountability mechanism

When and where were the activities carried out?

- Community Active Preparation, Jan 2005–Dec 2009, Bara
- PACED, July 2014–June 2019, Makwanpur, Parsa, Chitwan
- CEDAR, July 2009–June 2014, Ramechhap, Rautahat
- Socio Economic Rehabilitation, 2009, Province No. 3
- Livelihood and Income Generation, March 2016–June 2019, Kailali, Kanchanpur, and Bajura, Province 7
- RECLAIM, July 2012– June 2017, Nepal Leprosy Fellowship, Sunsari, Jhapa, Sarlahi, Province Nos. 1 and 2

Were persons affected by leprosy participating in the design and practice itself?

Yes, people affected by leprosy were involved in the design of the projects. Focus group discussion and participatory rural appraisal were conducted in the respective geographical areas before the design and implementation of the projects. TLM Nepal has leprosy affected persons as board members, whose opinion is sought before, during, and after completion of the projects. Moreover, IDEA Nepal, an association of people affected by leprosy, provides advice on need and on an ad hoc basis. TLM Nepal has a well-established project cycle management that is used as a monitoring tool to gather the views of people affected by leprosy on the projects. Through this tool, feedback from the people affected by leprosy is used for new learning and ultimately for the design and implementation of the projects.

Key implementers and collaborators

- The Leprosy Mission Nepal
- Government institutions: Leprosy control division, district health offices, local health posts, women and children office, cooperative division, local municipalities, agriculture office
- Non-government organizations: Disabled peoples organizations, National Federation Disabled in Nepal, and their local chapters

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Resource implications

- The above-mentioned projects were supported by TLM Global Fellowship (TLM Australia, TLM New Zealand, TLM England and Wales)
- Human resources involving people with knowledge and skills in leprosy, health and disability management, community-based livelihood and income generation, and project management were required to run the project

Results—Outputs and Outcomes

What were the concrete results achieved with regard to outputs and outcomes?

51 cooperatives that can access government funding were formed and linked with government agencies. There are 101 SHGs that manage services in the communities for savings and credit, physical self-care, emotional self-care, celebration of disability day, and celebration of World Leprosy Day. These cooperatives and groups have approximately 10,000 members. Among these members, approximately

- 70% have improved income
- 90% have increased participation in social activities (proxy indicators of reduction in stigma)
- 80% have improved hygiene and sanitation practices
- 15% have increased advocacy and leadership capacity in the communities

People affected by leprosy have taken leadership roles in these established groups and cooperatives and are helping to influence local, regional, and national level government with their enhanced capacity in advocacy.

All groups felt they had made a big impact on the reduction of both discrimination and stigma within their communities and were rightfully proud of their achievements. Time and time again, Group members mentioned how they were free to go out and that society had changed. Both women and men, as PWDs or not, felt they could go out and had the confidence to do so. As the Groups became more successful, then they would be acknowledged and appreciated, thereby becoming stronger in themselves, leading to both individual and group confidence (strengthening sustainability)

- End Term Evaluation Report of TLM PACED Project, 2019

Were data management processes of the best practice consistent and transparent to draw conclusions?

TLM Nepal has well-established data management tools and practices. There is a regular reporting system as a part of the project cycle management, which includes the key performance indicators reflecting participation of people affected by leprosy in the community. The International Leprosy Congress is one of the major events for TLM Nepal and includes several research activities that can improve understanding in the area of leprosy including stigma and mental health.

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Was an assessment of the practice carried out? If yes, what were the results?

CBR is a well-established practice to integrate people who have been displaced for various reasons back into their communities. People affected by leprosy are stigmatized by their health conditions, which leads towards debilitation. The CBR projects are assessed at different points of time, with well-established indicators of participation restriction score, poverty scale, and various other socioeconomic scores. These scores are compared at different time points using different assessment tools, which can show how change has been achieved. In summary, the projects undergo baseline, midline, and endline surveys to measure the impact of the practice.

Is the project completed or are some results still to be expected?

The projects have been completed.

Lessons Learned

Successes

- To change the perception and accountability of the government, the involvement of disabled people's organizations and other community members is necessary
- Collaborative work with other organizations/related stakeholders during the inception period of the project brings wider impact
- Participation of people affected by leprosy at different levels of project development and implementation worked well, and they were able to take ownership of the project.
- Capacity building in advocacy and leadership skills helps people affected by leprosy gain the confidence to raise their issues in different platforms
- Creating safe and accessible places and opportunities for people affected by leprosy to share their issues with their colleagues builds capacity and helps overcome ongoing problems
- Having SHG/cooperative members lead disaster risk reduction and other community development activities can open the pathway for more interaction and acceptance in the community and thus reduce stigma and discrimination

Limitations

- Only having people with disability, people affected by leprosy, or women in SHGs did not work well. The groups should be more inclusive so that the members can identify and work on more diverse problems and eventually have greater impact. Moreover, only having people with similar problems in the SHGs might trigger stigma and discrimination in the community.
- Sometimes within these groups, the outspoken members tend to take advantage over those who are shy and do not speak up for their needs and issues. While these SHG members always remain behind during the decision-making process, the decisions made by confident members may not necessarily be inclusive.

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Replicability and Scalability

Has the practice been implemented in more than one setting?

Yes, the learning and best practices of the past project has been incorporated in new projects and implemented in the other settings (e.g., lowlands–Tarai, and hilly region, and also among different ethnic groups).

What long-term effects can be achieved if the practice is sustained over time?

- People affected by leprosy and people with disabilities can be mainstreamed and contribute to the development of the nation
- People in the community will be aware of leprosy and its complications, and there will be
 - a reduction in disability and as people suspect leprosy and access leprosy services
 - improved health as people have confidence to access services before or after diagnosis of leprosy
 - improved socioeconomic status
 - improved mental health

What are the requirements to sustain the practice over time, considering contextual factors, institutional support, human resources?

- Participation of people affected by leprosy from very beginning of the project
- Leadership of people affected by leprosy in the project activities
- Ownership of the project by people affected by leprosy and other community members
- Capacity building for those lacking skills in advocacy and managing group activities
- Linkage and coordination with the government and other agencies
- Identification of local resources and mobilization of those resources
- Positive motivation of the members
- Appropriate supportive / assistive devices for mobility of people with leprosy disability
- Regular psychosocial/peer counseling from the beginning of the project in order to provide confidence that they are part of the community

Conclusions

How have the results benefited the population?

The SHGs/cooperatives have benefitted the wider community since their activities are inclusive. The disaster risk reduction and emotional care activities that are embedded within the group activities involve the local government and other stakeholders. The participation of different stakeholders helps to dispel myths and harmful practices and to overcome negative perception towards different marginalized groups, including people affected by leprosy. This can help bring harmony and understanding in the community.

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Through these projects, people affected by leprosy and people with disabilities have been empowered to contribute to their families and communities. As their confidence increases, they are leading various development activities that benefit the wider community. Several structures like community toilets and community water resources have been built through initiatives of the group members. These groups have also become an access route for TLM Nepal, helping to reach wider communities such as when Nepal was struck by earthquake in 2015. This has resulted in thousands of members joining the groups formed in the mission's initiative.

People affected by leprosy who are trained in suspecting leprosy cases can refer clients to appropriate health centres. As these groups are trained in different community issues, they have become referral and connecting points for the various issues and needs in the community.

These groups are also connected with local government institutions and other stakeholders involved in development. The benefits are shared and received not only by the members of the group but by the wider community.

The work of the group members with interfaith groups in the communities can help overcome stigma and discrimination in the communities.

Why may that intervention be considered a “best practice”?

- Having inclusive community members participate in group activities can play a pivotal role in changing the attitudes of community members towards people affected by leprosy. The group challenges the misconception that people with leprosy and disabilities are unable to study, learn new skills, get married, have children, and work for living.
- SHGs/cooperatives operating in a business model provide opportunities for people affected by leprosy to have easy access to microcredit services
- SHGs/cooperatives provide members an opportunity for personal growth and advancement in different areas of life (e.g., social, family, economic, and emotional) and give confidence to the associated members
- SHGs are a platform for various community activities, including raising awareness on leprosy and helping to reduce harmful cultural practices that affect the wellbeing of the most vulnerable in communities
- SHGs enable members to stand up for their rights at the local level (in the communities). The unified voice of people affected by leprosy/disabilities is stronger than an individual's voice
- SHGs are safe places to build leadership quality of people affected by leprosy who are otherwise marginalized
- Constructive community activities and businesses led by people affected by leprosy have played key roles in integrating community members and people affected by leprosy, changing community-based misconceptions about leprosy disease and associated stigmas

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What recommendations can be made for those intending to adopt the documented “best practice” or how can it help people working on the same issue(s)?

Information from the evaluation (midterm and end-term) report of the SER project, CEDAR projects, and PACED projects showed that

- Proper community assessment should take place before the formation of group or planning group intervention. Participatory rural appraisal and other social appraisal tools can be helpful in understanding community dynamics and needs. People affected by leprosy and people with disabilities should have active participation.
- The members of the group should be from diverse backgrounds (people affected by leprosy, people with disabilities, single women, and care takers of people with disabilities, etc.). This helps to capture diverse issues related to stigma and discrimination and other factors that cause societal discrimination.

Further Readings

Footsteps: Living with Disability. 2019; 108. Available at

https://learn.tearfund.org/en/resources/publications/footsteps/footsteps_101-110/footsteps_108/

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