
ANNUAL REPORT 2019

Advancing Health and Ability



until
No Leprosy Remains

Who we are

NLR Nepal is a non-profit, non-religious & non-political development organization working in Nepal for over 40 years. It promotes health, specifically in making the country free of leprosy and inclusion of persons affected by Leprosy by enhancing their ability. NLR Nepal supports Governments & local NGOs in carrying out different project activities including leprosy control & disabilities inclusive development. The emphasis is primarily on changing of the behavior, relationships & actions of local Government and non-government partners through capacity building. NLR strives to work and coordinate activities consistently with other likeminded national and international organizations.

NLR Nepal is guided by the eighth project agreement (2016-2020) made with the Social Welfare Council and is currently contributing support to Leprosy Control, Disabilities Management & Inclusion in Nepal.

Our Vision

A world free of leprosy and its consequences

Our Mission

We prevent, detect and treat leprosy and support health, ability and full inclusion in society for persons affected by leprosy.

Strategy

NLR Nepal is undertaking the program activities guided by NLR Multi annual strategy for the project period 2020-2022. It implements its projects through the Boundary Partners (BPs) fulfilling the requirements set by the Government of Nepal. We have considered globally adopted three zero strategies (zero transmission, zero disabilities, zero exclusion) as major pillars and set the main targets of this project period. NLR focuses on reducing disease burden due to leprosy, promotion & demonstration on effectiveness of preventive measure in leprosy through PEP interventions, mainstreaming of leprosy to general development agendas as guided by SDG & other relevant National/International policy and provisions and reducing the stigma and discrimination through integrated development approach.

Abbreviation

CBRF	Community Based Rehabilitation Facilitator
DID	Disability Inclusive Development
DPO	Disabled People's Organization
EDCD	Epidemiology and Disease Control Division
KPP	Key Priority Programme
LCDMS	Leprosy Control and Disability Management Section
LPEP	Leprosy Post-Exposure Prophylaxis
MB	Multi Bacillary
NTDs	Neglected Tropical Diseases
PAC	Project Advisory Committee
PB	Pauci Bacillary
SDR	Single Dose Rifampicin
SWC	Social Welfare Council
WHO	World Health Organization
GPZL	Global Partnership for Zero Leprosy
NPZL-NTDD	Nepal Partnership for Zero Leprosy, NTD and Disability
BP	Boundary Partner
SDR-PEP	Single Dose Rifampicin Post exposure Prophylaxis

Message from Country Director

Dear Partners, Co-workers and friends,

It is my great pleasure to share our work through this annual report 2019 and I am delighted to tell you all that we were able to deliver our services despite of many challenges including the change in structure of authorities and administrative wings of Nepal.

We are in stage of enthusiasm with the establishment of NLR Alliance evolving from NLR working with branch offices in five countries including Nepal which will operate on the basis of multi-faced collaboration between members sharing the history, skills and expertise to fight against leprosy. We are working in line with the five-year (2016-2020) project agreement signed with the Social Welfare Council and the multi annual strategy prepared in the year 2019 for the 3 years 2020-2022.



Like previous year our main activity targets were directed towards innovative approaches both in leprosy control and disabilities inclusive development. To support Leprosy Control Program, SDR-PEP remained the major focus also in 2019. Till the end of 2019 (2015-2019) a total of 62,611 persons are provided with Single Dose Rifampicin (SDR) out of the 68,976 contacts screened tracing of 2,918 index cases. We are able to do this intervention the SD-PEP in 19 districts out of 23 districts of our working area and the remaining 4 districts will be covered in the year 2020. The LPEP piloting has been wrapped up in December 2018 and the dissemination was done in early 2019 in presence of Government high officials, international experts and supporters.

In 2019 the in-depth review of the leprosy program was done and a road map as a first of its kind was prepared based on the in-depth review in collaboration with the WHO and Global Partnership for Zero Leprosy led by the Government of Nepal, Ministry of Health. NLR Nepal is happy to be a part of review process and developing a road-map. Our experiences working with 15 municipalities has been a very encouraging one since the NLR Nepal concept and the objectives are now fully owned by the local Government and is well appreciated.

I am pleased to convey the message that our relationship with the government, international partners and other stakeholders has been very good during the year. With our little effort ILEP supported organizations working in Nepal has formed a consortium platform in the name of Nepal Partnership for Zero Leprosy, Neglected Tropical Disease and disability (NPZL-NTDD).

For our achievement, I would like to thank the Government authorities, all the international and national partners, well-wishers, co-workers and staff members for their consistent technical, financial and moral support given to NLR Nepal.

*Sincerely,
Himalaya Dev Sigdel
Country Director*

Major Projects in 2019

- ✓ **Stop Transmission of Leprosy**
- ✓ **Prevention of disabilities**
- ✓ **Disability Inclusive Development**

Stop Transmission of Leprosy

Summary

Numbers of districts covered	18
Numbers of Municipalities covered	108
Numbers of index cases covered	985
Numbers of contacts listed	17632
Contacts per index cases	18
Numbers of contacts screened	15644
Numbers of contacts excluded	1686
Number of contacts with SDR administration	13965
Numbers of leprosy suspected cases	46
Numbers of leprosy diagnosed	5

Nepal is one of the leprosy endemic countries in the world. Disease burden due to leprosy together with new cases detection rate is comparatively higher in the province 1 and Sudurpaschim province. According to LCDMS reprot, out of total new cases detected, 27% were detected from NLR supported provinces. Child proportion & disabilities due to leprosy is still common in those areas. NLR Nepal jointly with Government health setup & NLR's boundary partners initiated Leprosy Post-Exposure Prophylaxis (LPEP) in two districts of province 1, demonstrating very appreciative results on contributing stop transmission of leprosy. That had encouraged all to replicate in all remaining districts of province 1 and Sudurpaschim province and also encouraged all related organizations of Nepal to start SDR-PEP in their respective working areas.

In the recent years' development, WHO has incorporated such preventive approach whereas the country strategy of Nepal 2016-2020 has given higher priority on rolling out SDR-PEP interventions throughout the country. The main added value of this is enhancement of contact tracing together with preventive measures to population at higher risks of leprosy and promotion of early cases detection. Further, SDR-PEP interventions has shown greater strengths on mobilizing or enhancing community participation on leprosy. In this way, on promoting innovative approach for stop transmission, putting additional effort for regular

leprosy control activities (MDT services & compliances) and then promoting integration & reversal integration on leprosy complication management may create a better environment to achieve leprosy free communities.

Annual case detection rate in 2019 as per national data has been recorded to be 9.66 in Province 1 and 9.28 in Sudupaschim Province per 100,000 population. In NLR working area 5 new cases were discovered in 2019 through SDR-PEP intervention. However, as per national data child proportion among new cases is 4.88 in province 1 and 4.89 in Sudupaschim Province. Likewise, proportion of Grade 2 Disability is reported as 1.49 in Province 1 and 6.02 in Sudupaschim Province. Additionally, female proportion among new cases are 32.48 in Province 1 and 36.84 in Sudupaschim Province.

After the completion of Leprosy Post-Exposure Prophylaxis (LPEP) piloting project that NLR Nepal jointly with the Ministry of Health started in 2015, till 2019 a total 19 districts are covered with PEP intervention on leprosy in Nepal. Those districts are; Panchthar, Ilam, Dhankuta, Sankhsava, Solukhumbu, Terathum, Okhaldhunga, Khotang, Taplejung, Bhojpur, Jhapa, Morang, Udayapur, Kailali, Kanchanpur, Achham, Doti, Bajhang and Bajura. Local government has been totally convinced on efficiency of SDR-PEP intervention program in controlling leprosy and they have become more aware about the issue. They have separated fund for the SDR-PEP administration and has precisely prioritized the program in their planning document. One of the 15 municipalities, Yangwarak municipality is preparing to declare itself to be a 'Leprosy Free Municipality' in 2020.

Prevention of Disabilities

Summary

<i>Best Wishes orientation to HWs</i>	71
Best Wishes orientation to FCHVS	29
Data Colletion of Pregnant Women	4392
Distribution of Best wishes cards to newly married couples	1878
Distribution of Best wishes cards to pregnant women	3138
Pregnancy registration by FCHV(Mobile)	520
Pregnancy checkup, regular follw up by A.N.M	2548
Best Wishes review program	6
Mothers group's regular meeting	1766
folic acid & nutrition orientation to golden 1000 days mothers	70
Nutrition program for malnoursh children (kitchen garden concept)	23
Refer malnourish children	111
orientation on by birth deformity to golden 1000 days mothers	70

Disability prevention is one of the project proposed in this context that covers prevention of disabilities by birth as well as prevention of further worsening of impairments. Disability itself is the result of interactions between impairment & environmental barriers which is clearly covered under the project disability inclusive development.

Disability prevention (Inspire2Care) is a project that focuses on prevention of birth related impairments/disabilities (by birth & during birth). This focuses on activities concerning improvement of maternal and child health i.e. promotion of registration of pregnancy in health institution, pregnancy care including nutrition, immunization and regular antenatal checkup, delivery planning and institutional delivery, awareness activities. This project emphasizes on identifying children with impairment/disabilities with their detail assessment and develop individual rehabilitation plan to provide intervention as per the plan for each child based on the individual assessment.

The long term objective of this project is to decrease number of birth defects and preventing worsening & further worsening of impairments by strengthening existing health system and educating communities with deepened focus to vulnerable groups.

Till 2019, all 15 municipalities in Province 1 and 7 within NLR Nepal's working area have fully functional of Inspire2care project. There were predefined 100 activities within this project with numerous outputs that ultimately helps to quantify and measure the overall impact of the project. Required number of Community Based Rehabilitation Facilitators (CBRFs) have been recruited in all 15 municipalities to conduct the listed activities. Best Wishes Program for newly married couples as well as pregnant women are distributed by these CBRFs during their community visits and check whether prenatal check-ups have been conducted timely.

Disability Inclusive Development

Summary

Numbers of Municipalities with General & annual project agreement with NLR Nepal	15
Numbers of CBRFs (Community based rehabilitation facilitators) recruited	51
Numbers of Municipalities with census survey using 'Online Palika'	7
Numbers of Municipalities with long-term plan and municipality profiles	7
Numbers of Municipalities allocating resources (matching fund) for DID program	15

After restructuring of the country into three tier governmental system (federal, provincial & local – Municipalities) mainstreaming of leprosy (as medical as well as social problem) as cross cutting issues of wholistic development program seems quite relevant. On making leprosy as a strong issues within development practices & managing for proper resources allocations with priorities, NLR Nepal has initiated 'Model work Municipalities on inclusive development' as some of the demonstration sites for further replication to remaining areas of the country. The major focus of this project, Disability Inclusive Development program is inclusion through proper participation in mainstream development program of deprived or pro-poor populations where as leprosy effected persons & persons with disabilities are taken as main priority target groups.

Local government has taken the ownership of of inclusive development program, recruited community based rehabilitation facilitators (CBRFs) and successfully established the baseline information using MIS software named 'Online Palika'. Sharing and mutual learning of best practices among the Municipalities were conducted through review workshops. Baseline establishment is completed through census survey in seven Municipalities where as three Municipalities are under processing.

Local Government authorities have now fully understood the purpose & rationale of Inclusive Development concept and consequently, many transformations & modifications are being observed on disabilities inclusive developments (DID) & comprehensive WASH areas. Development of proper planning & allocation of resources in equitable basis has become another achievement in many areas of development including leprosy & disabilities.

Advocacy & lobbying at the policy level, networking, empowerment and capacity building are the major aims of this project. Persons with Disabilities can receive the required services such as treatment and devices, either from Government schemes or existing rehabilitation centers and the organization like National Federation of Disabled Nepal (NFDN) can establish the linkage for the same.

Other Events

Leprosy Post-Exposure Prophylaxis (LPEP) Dissemination Program

After the completion of the 3 years LPEP program, the dissemination program was organized successfully in presence of Ministry of Health authorities, International LPEP coordinator, Erasmus University representative and the donor, The Novartis Foundation. The SDR-PEP has been rolling out continuously even after the completion of pilot project. NLR has been the pioneer in initiating and



implementation of SDR-PEP and has been appreciated from the Government, International Office and the funding agency, the Novartis Foundation. 93% of the NLR working area has been covered by SDR-PEP and rest will be covered within the first 6 months of the year 2020. All the leprosy organization working in Nepal has received the SDR-PEP ToT training provided by NLR Nepal. This year, leprosy inventory of persons affected by leprosy has been established with GIS mapping with all required information (100% of low endemic and >90% of endemic districts).

International Workshop on Disability Inclusive Development

A three days International Workshop on KPP3- Inclusive Development program was organized from 12th to 14th November, 2019 with a total of 13 Participants (Nepal - 5, Netherlands - 2, Mozambique - 2, Brazil - 1, Indonesia - 1, Mekong - 1, India -1). The objective of the workshop was to share the current status of Inclusive Development projects from each country. Each country representatives



shared best practices, lessons learnt and challenges faced during project implementation. Discussion was held among the participants on ways to maximise the participation of leprosy affected persons in each project and ways to incorporate Theory of Change (ToC) in near future. Along with the reflection on Inclusive Development program/zero exclusion for coming

year, the workshop intended to develop NLR strategy on Inclusive development program for 2020-2022.

Team Building and Training on Appreciative Inquiry

A one day event on team building was organized on July 15, 2019 at Dhulikhel for entire NLR Nepal staff members. The purpose of the event was to build better communication and coordination among NLR Nepal staff members for efficient organization culture. This event was followed by a one and a half day training on Appreciative Inquiry based on the need of positive inquiry in project implementation.



TOT on Leprosy

A two days Training of Trainers on Single Dose Rifampicin Post Exposure Prophylaxis (SDR-PEP) was organized on 31st October to 1st November 2019 in Kathmandu with 15 participants. The TOT program was intended to stimulate the clear understanding of technical as well as managerial aspects SDR-PEP to the boundary partners, stakeholders and the government officials. The



The objective of the program was to decide on clear pathway of SDR-PEP interventions and develop a M&E framework and toolbox for the same.

20th International Leprosy Congress, Manila

The 20th International Leprosy Congress took place in Manila from September 10th-September 13th. A delegation of 3 NLR staff was present and actively participated and contributed to the conference. The entire conference had presentations on leprosy through various dimensions that were refreshing. NLR colleagues were fascinated by the fact that social science could be an effective perspective to evaluate our work on health intervention and we could learn a lot about the best practices from other countries. NLR Nepal presented 4 papers in the conference.

1. Evidence of the feasibility of Post Exposure Prophylaxis (PEP) from the LPEP Pilots in Nepal: An inspiration for scaling up
2. Integration of leprosy control and leprosy chemoprophylaxis in an inclusive development programme with disability prevention, disability management and comprehensive wash – A preliminary experience from Nepal.
3. Social Exclusion/Inclusion and livelihood status of Leprosy affected people in Nepal-A case study of Jhapa and Udayapur districts
4. Characteristics of newly detected cases of Leprosy in Districts where Post Exposure Prophylaxis (PEP) was implemented: A Case-based study from Nepal.



Global Partnership for Zero leprosy

NLR Nepal played a significant role in establishing relationship with Global Partnership for Zero Leprosy (GPZL). A separate session was arranged in Manila during the 20th International Leprosy Congress, to discuss possible support to Nepal on behalf of GPZL. With support from GPZL and WHO, the National indepth review and development of roadmap was done. The proces was led by the government of Nepal. NLR Nepal provided extensive support to the indepth review and development of roadmap and a letter of appreciation was also awarded for the same.

Multi-Annual Planning Meeting

The country multi & annual plan for 2020 - 2022 has been prepared involving the entire NLR Nepal staffs, NLR Nepal national organization's board members, representatives from leprosy affected peoples' organizations & BPs anticipating their valuable ideas, feedback and recommendations. Activities, targets and indicators has been designed to be more specific and feasible in terms of implementation in newly formed administrative divisions of Nepal, namely "Federal", "Province" and "Local" (rural/urban municipalities) levels. While preparing the annual plan, recommendations were also sought from different government officials in program areas (municipalities) to ensure more practical and elaborated methodologies to accomplish the targets.



Inclusive Development Review Meeting

This year, with joint collaboration of NLR Nepal & rural/urban municipalities, two sharing and review meetings on Inclusive development program were organized with the Chairperson and Vice-chairperson of all 15 municipalities. The review meeting included chair, vice chair and IT officer from each municipalities to discuss the progress towards Inclusive development program and challenges faced. The two days program intended to share best practices from each municipalities and replicate them to others as per the context.



Online Palika

This year NLR Nepal introduced a MIS system named 'Online Palika' to manage the existing database about census and to conduct online/offline survey in different municipalities within NLR working area. The data collected has helped local government authority to develop long-term plan on the basis of current context and make decision to strengthen municipal services. By creating and managing the database, NLR Nepal has promoted and supported the health, ability and full inclusion in society of people affected by leprosy and persons with disabilities.

PAC Meetings

Central level, districts level and municipality level Project Advisory Committee (PAC) meetings were organized in order to update the status of each projects to the SWC, concerned ministries and stakeholders in place. Major recommendations were noted and action towards those recommendations had been reported to the concerned authorities in given time frame.



NLR Nepal as a National Organization

A national organisation with a new chair and competent board has been registered under the Government Act as a Profit- Not Distributing organisation of Nepal after the finalization of Memorandum of Association (MoA) and Article of Association (AoA). The process started from

2016 and progress has been amplified in forming the national board with proposed chair and members. There are six members in the board including two female members. The national organization is fully functional from 2019.

A legal advisor has been appointed, who has been advising and supporting the transition process to ensure compliance with the Government of Nepal regulations. Three formal board meetings have been held after the registration and all the legal formalities have been completed. The organization is registered in Social Welfare Council (SWC), Kathmandu Metropolis, tax office and local ward. A bank account has also been opened in Nabil Bank Limited as decided by the board. Although there was almost negligible transition, an audit report is required for the Nepali Fiscal year 2075/76 and was done in October 2019.

Central Support and Services

Funding and Finance

In the year 2019, NLR Nepal's total income was NRS. 52,290,100 (Euro 4,13,091) and consolidated expenditure remained NRS. 52,224,887 (Euro 4,12,576). The consolidated budget includes full accounts of Biratnagar and Dhangadi field offices. The funding has been entirely supported by NLR International Office, Amsterdam and NOVARTIS Foundation. As a new line of reporting, 'Navison' has been established as a financial reporting system from 2019.

Branding and Communications

We are happy to share that this year we have initiated branding components with support from Brand Manager at International office. Many activities have taken place this year including new website development and management, design and printing of communication/brand materials (flyers, project briefs, brochure, and public annual report 2018).

Quarterly Review Meeting and performance appraisal

Participatory review meetings with NLR staffs and the partners and the right holders had been organized in each quarter. The individual monthly planning and the reporting system was continued to track the functioning of our staff. Performance appraisal of all NLR staffs was conducted twice by respective line managers in an individual session.

Institutional Fund Raising

NLR Nepal has initiated the establishment of a consortium of six organizations working in the field of Leprosy, other NTDs and disability aimed at joint fund raising and program implementation. The partnership MOU / agreement was signed with the objectives, terms of conditions, and the roles and responsibilities of consortium partners. The consortium partnership has been named as Nepal Partnership for zero leprosy, NTD and disability (NPZL-NTDD).

Boundary Partners

The coordination with Government especially with Leprosy Control and Disability Management Section is very well. Likewise the coordination with provincial Government and local Government (15 municipalities) is very good. The regular communication including the partner's review meeting has been done with the boundary partners, NNSWA, NFDN and NLF. The coordination with like-minded organizations (ILEP and non-ILEP members) is also improved compared to last year.

Outcome Mapping (OM) Approach

The monitoring and evaluation system (M&E) based on the Outcome Mapping/Outcome Harvesting has been in place since past three years which has been strengthened with an electronic data base Outcome journals and Strategic journals are the main tools for monitoring project outcomes.

NLR Nepal has adopted OM as PME tool for this project period where as main focus of OM is outcomes, which relates to the changing knowledge, attitude, action/policy and relationship of BPs. In this regards, main focus of the program is strengthening the capacities of BPs. To ensure sustainable results in the intervention areas, regular review of organizational practices and strategy maps and assessing the BPs functioning through outcome journals are the major practices.

Stories from the field

Case Study

Rapat Lal Rajbanshi was living a content life with his wife and three children in of Gherabari-2, Kachankawal in Jhapa district. He worked hard in his small land plot to grow wheat, paddy and maize. The produce from this land was barely sufficient for livelihood of his family.

In 2017, Rapat was diagnosed with cancer. He spent a lot of his savings in his treatment and lost his leg to cancer. He had to go under prolonged treatment that included cutting off the infected leg. He struggled with financial crisis in his family when he couldn't work in his field like he did before. He couldn't walk around and was hopeless to have lived.

Later his condition was known to Community Based Rehabilitation Facilitators of Kachankawal municipality while conducting municipality census survey. They immediately linked him to the municipality office and recommended for an assistive device to replace his leg.

The municipality authority provided him with a pair of crutches. This made him easier to walk around his neighborhood. Later he was referred to a camp organized by Marbadi sewa samaj in Arjundhara, Jhapa. The camp was for the distribution of assistive devices for the persons with disabilities. With recommendation from Kachankawal municipality, Rajbansi was able to receive an artificial leg from the camp.



Case Study

A nine years old, Tirtha bahadur Thapa, was growing up with cerebral palsy. His parents tied him to his bed before they left for work every morning. Coming from a poor family they could not afford his treatment in a bigger hospital. His condition worsened with him growing up. He was unable to go to school. He depended on his parents for everything.

While conducting the household survey for data collection of persons with disability, a community based rehabilitation facilitator (CBRF) linked the child's parents to the Belaka municipality office. Belaka municipality was working towards providing disability identity card and assistive devices to the persons with disability within the municipality.

After few stages of treatment, he received a wheel chair as a assistive device support from Belaka Municipality. He started going to school using it and has been performing well as reported by his teacher. He is surrounded by his friends and they have been supporting him when he cannot get into his wheelchair from his class bench. He expresses his happiness with a smile on his face and dreams to become a health worker in future.



Case Study

"My name is Hem Gharti Magar and I am from Kailali, Province 7 of Nepal. I had senseless patches down to knee and had no sense in right foot. I visited nearby medical store where I was provided with some medicines but it never recovered and instead was spread all over my right leg. Later I noticed some abscess around my leg and I panicked.

One of the Female Community Health Volunteer (FCHV) in my community suggested me to visit a person named Man Bahadur at Health Post. He was responsible for diagnosis and treatment of Leprosy at the health post. Before I could visit the health post, the person himself came to see me at my house and provided preliminary treatment and then he referred me to the Seti Provincial Hospital in Dhangadi for further treatment.

At the provincial hospital, I was diagnosed with Leprosy and was given medical treatment for 12 months. After the treatment, I feel much better. Only issue that I was bothered with was the behavior of my family members and neighbors towards me after knowing about my disease. I discussed about it with Man Bahadur and he conducted a one-day awareness program on Leprosy and its treatment and also explained about preventive measure to all the contacts with single dose rifampicin. Now, I feel more comfortable to walk around my community and talk to people. My family members take good care of me and they are not scared to touch me and talk to me. Very soon, I am planning to start a small business of my own."



NLR Nepal would like to acknowledge the following organizations for their support this year

Social Welfare Council

Leprosy Control and Disability Management Section, Epidemiology and Disease Control Division, Ministry of Health

NLR International Office, Amsterdam

Association of International NGOs in Nepal (AIN)

NOVARTIS Foundation

Erasmus Medical Center

National Federation of Disabled Nepal (NFDN)

The Leprosy Mission Nepal (TLMN)

Nepal National Social Welfare Association (NNSWA)

Municipalities of Province 1

Municipalities of Sudurpaschim Province

Global Partnership for Zero Leprosy (GPZL)

World Health Organization (WHO)

Nepal Partnership for Zero Leprosy, NTD and Disability (NPZL-NTDD)

Social Development Ministry of Province 1 and Sudurpaschim Province