ADVANCING HEALTH & ABILITY

Support to Leprosy Control, Disabilities Management & Inclusion in Nepal

ANNUAL REPORT
2016

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FOREWORD

Dr. Krishna Prasad Dhakal
Country Director
NLR Nepal

Dear Readers, Partners and Co-workers,

It is my great pleasure to present Netherland Leprosy Relief Nepal (NLR Nepal) report for the year 2016. This year has been a difficult time to the people of Nepal because of political instability and residual effect of the disaster occurred in 2015. The people of Nepal are optimistic that with the new constitution and newly elected future leaders make a better future and a peaceful life to live in the country.

A new five-year project for the project period 2016-2020 was developed in Outcome Mapping (OM) approach which got approval from Social Welfare Council (SWC) and was signed on June 2016. After signing of the project document, NLR Nepal started to implement its projects through Boundary Partners (BPs) fulfilling the requirements set by the Government of Nepal.

Main activity targets were directed towards innovative approaches both in leprosy control and disabilities management. Leprosy post exposure prophylaxis project is running well with over 31 thousand contacts of more than 1200 index cases enrolled and fed SDR. In the capacity development area, over 1670 health workers and volunteers were provided training in leprosy. In service delivery 380 persons with leprosy and disabilities were provided with some sort of livelihood support and over 500 received medical and surgical help.

Mainstreaming of disabilities due to leprosy into general disabilities were continued with continuous training activities; advocacy and lobbying at different areas; changing attitude, behavior, action/policies & relationships of BPs. Newly introduced technology of leprosy prevention, LPEP, will be continued whereas further expansion of the districts has been prepared. NLR Roundtable (RT) set four priority areas were fully considered and activities are planned accordingly.

I am pleased to say that we have been able to achieve most of the targets fixed in the plan made for 2016 despite of internal and external factors especially delaying in agreement with Government of Nepal. For this achievement, I would like to thank Dr Basudev Pandey, LCD Director for his generous support, Ms Mithilde Vandenbooren and the entire team of NLR International Office for their continued technical and financial support to ensure the smooth running of the projects in Nepal. My especial thanks goes to all the partners and staff members of NLR for their hard work and dedication towards the well being of the patients, clients and their families.

I hope you will find this report interesting and helpful for a clear understanding of NLR works in Nepal. We welcome any comments and suggestions about this report and our work.

Thank you.

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LIST OF ABBREVIATIONS

CBR	Community-Based Rehabilitation
CDR	Case Detection Rate
DDC	District Development Committee
DG2	Disability Grade Two
DPO	Disabled People's Organization
DTLO	District TB Leprosy Officer
EDP	External Development Partner
EDR	Eastern Development Region
FWDR	Far West Development Region
GESI	Gender Equity and Social Inclusion
GON	Government of Nepal
ILEP	International Federation of Anti-Leprosy Associations
LCD	Leprosy Control Division
LPEP	Leprosy Post Exposure Prophylaxis
MDT	Multi Drug Therapy
MOHP	Ministry of Health & Population
MoU	Memorandum of Understanding
MWASD	Ministry of Women, Children and Social Welfare
NFDN	National Federation of the Disabled Nepal
NGO	Non-Governmental Organization
NLCP	National Leprosy Control Program
NLR	Netherlands Leprosy Relief
POID	Prevention of Impairment and Disability
PWD	Persons with Disabilities
PWDL	Person with Disability Due to Leprosy
RFT	Release from treatment
SDR	Single Dose Rifampicin
SWC	Social Welfare Council
ToT	Training of Trainer
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
VDC	Village Development Committee
WHO	World Health Organization

INTRODUCTION

General Information

The history of NLR dates back to 1967 when Ms. F.M.J Antem and Dr. D.L. Leiker

- NLR started to work in Nepal in 1979
- Works in leprosy control, disability management & inclusive development
- Worked in 27 districts of Nepal in 2016
- Number of employees - 17

being motivated by their real experience with the leprosy affected people in developing countries took the initiative to establish the organization committed to serve leprosy patients and people affected by leprosy. Leprosy affected people did not have adequate access to treatment and they had to undergo through horrible isolation, discrimination and stigmatization.

Netherlands Leprosy Relief (NLR) is a non-profit, non-religious INGO which operates in 5 different countries; Nepal, Mozambique, India, Indonesia and Brazil through 5 country offices. NLR is a member organization of the International Federation of Anti- Leprosy Associations (ILEP).

Vision

A world free of leprosy and exclusion due to disabilities.

Mission

NLR promotes and supports the health, ability and full inclusion in society of people affected by leprosy and persons with disabilities.

Strategy

NLR works with governments, NGOs, research institutions and Disabled People's Organizations (DPOs) to promote the accessibility and quality of services via the provision of training, expert advice, research and innovations NLR develops its policies and programs in accordance with National policies harmonizing with the programs guided by different UN Conventions and other developmental agendas such as UNCRPD, MDG/SDG, CEDAW, CRC.

NLR lobbies to focus for "Inclusion (enhancing opportunities, ensuring equal rights and reducing barriers)" on policy agendas at all levels.

NLR in Nepal

In Nepal NLR 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 Boundary Partners through capacity building. NLR strives to work and coordinate activities consistently with other strategic partners or international organizations.

NLR started its operation in Nepal in 1977. Since then, the organization has evolved with various strategic phases in different course of time. NLR's operational approaches in Nepal can be segregated into various strategic eras;

Establishment Era (1977- 1986): NLR with a project office Biratnagar had a contact office in Kathmandu manned by one liaison officer. Functionally, NLR focused its support on leprosy services in eastern region of Nepal and as per the request of government, it also constructed hospitals and health posts in seven districts of eastern and mid-western regions of Nepal such as Tehrathum, Taplejung, Panchthar, Dailekh, Rukum, Jajarkot, Rolpa.

Treatment Era (1986- 2000): Leprosy treatment initiatives were extensively launched and resources were consolidated for patient diagnosis, treatment and care through leprosy clinics, mobile camps as well as government health posts. Structurally NLR continued a liaison office in Kathmandu and started its operation in Far-western region in 1991 and at leprosy control division in 1994. NLR started its' support to TB control program in far west region in 1995.

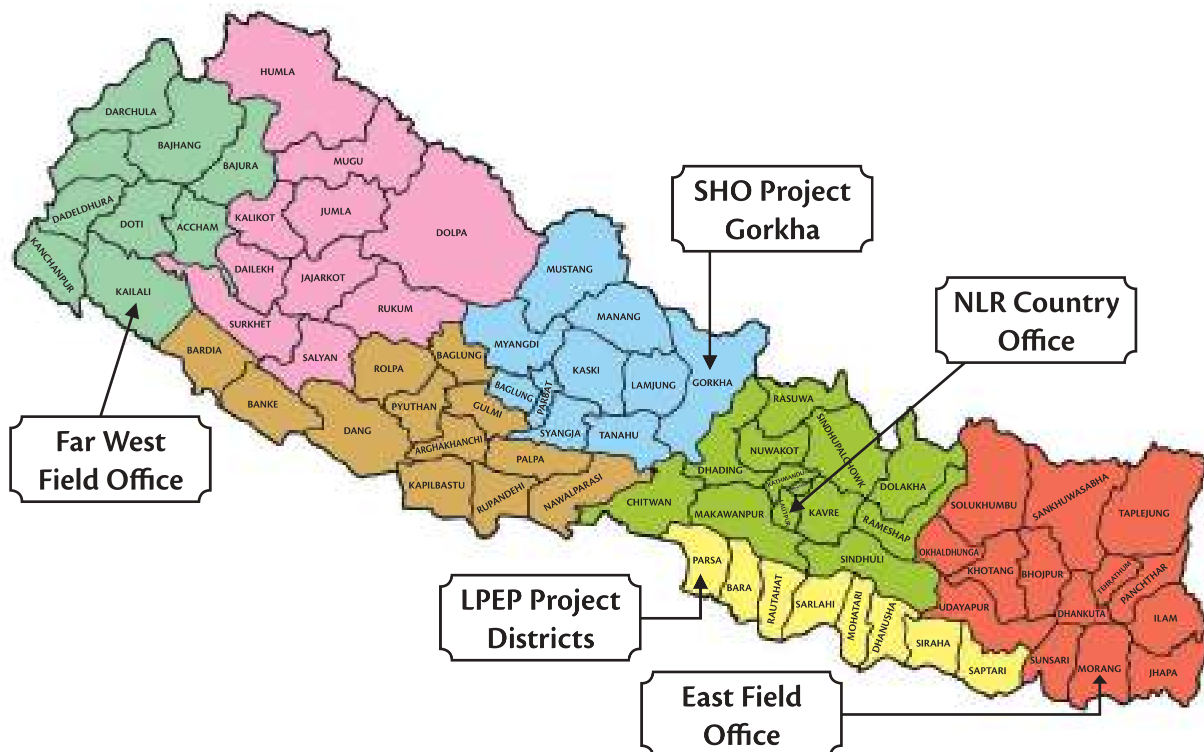
Leprosy Control Era (2000- 2005): In context of integration of leprosy control program into PHC system by the government, disease & disabilities prevention due to leprosy, awareness raising in the communities, training & capacity building of government staff in service provision, establishing & updating of self-care/self help groups were the major supporting activities during this era. Providing special leprosy expertise services were continued from two regional referral clinics always remained one of the main activities of the organization.

Transformation Era (2005- 2010): NLR Nepal underwent a paradigm shift both structurally and functionally. Structurally, NLR established its country office in Kathmandu and all individual regional projects were brought under the umbrella of NLR Nepal program. For the first time NLR underwent its agreement with Social Welfare Council. NLR Nepal, keeping leprosy control as its core business, widened its scope of intervention and prioritized mainstreaming of leprosy to general disabilities and then disabilities to holistic developmental perspective.

Development Era (2010 onwards): NLR Nepal still keeping leprosy control as one of its core business brought disabilities as another key business and further widened its areas of support to developmental issues such as comprehensive WASH, NTDs, Inclusion, inclusive education, disabilities inclusive disaster, prevention of birth related disabilities through Inspire2Care and so on.

NLR Nepal Working Area

NLR Nepal with its support activities in leprosy, disability and other issues of development covers all the districts of Eastern and Far west regions with an extension to Parsa for Leprosy Chemoprophylaxis project (LPEP) and in Gorkha for Disability Inclusive Development (DID) and Disability Inclusive Relief and Rehabilitation (DIRR) project.



Leprosy Control

Leprosy control program runs through the regular PHC service delivery system through the Leprosy Control division of Department of Health Services. NLR has, as usual, provided financial support through government RED BOOK as well as direct support through boundary partners including financial and technical support as per need.

The developments in the field of health services such as new long term health plan, post MDG strategies for sustainable development, new 5 years strategic plan for leprosy program, 10 years strategy for disability prevention and rehabilitation, development of CBR guidelines, approval of new education act, drafting of new disability act are some of the policy development works done in leprosy and disability areas in Nepal where NLR had inputs.

Leprosy situation in NLR working area during 2016

- New cases detected during the year – 934
- Released from treatment – 887
- Child cases - 46
- DG II cases - 26
- Female cases among new - 387

NLR renders support to leprosy control services through the national level Leprosy Control Division (LCD) of Nepal. To strengthen the national leprosy control unit, NLR provides technical expertise in the form of expert staff, and training of health workers in the field. NLR Nepal also provide funds to implement active case detection activities, monitoring of the program activities, and drugs for complication management. In addition, NLR provides support in research and studies to ensure evidence based practices. Beside this, NLR provides technical expertise HR and other essential supports to the two leprosy referral centers conducted by Koshi and Seti Zonal Hospitals in Eastern and far western regions respectively.

The leprosy Post Exposure Prophylaxis (LPEP) program which was initiated by NLR in three

Leprosy Case Detection

districts together with the National Leprosy Control Program, continued to progress in 2016 as well. Its achievements have been appreciated in national and international forum; so that; supporting activities through GON/NGO partners are designed accordingly. Currently this prophylaxis program has been expanded by government and other ILEP partners including NLR to five more districts. Detail discussion on this program (LPEP) is given further below in this report.

In the area of POID, apart from early case detection, early detection and management of reactions and wound care and surgeries in hospitals and clinics; self-care/self-help group concept is functioning well at village level taking appropriate steps for the rehabilitation of persons with disabilities including disabilities due to leprosy in CBR modalities and right based approach. NLR role as a facilitator and also providing need based financial and technical support through its boundary partners remained continued.

National and Regional Level Indicators – 2016

Trend of important indicators of leprosy

	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
NCDR	16.5	16.7	16.6	11.5	11.2	12.2	11.9	11.8	11.01	10.67
PR	1.45	1.42	1.09	0.77	0.79	0.85	0.82	0.83	0,89	0.89
DG2%	5.62	4.14	3.9	2.72	3.47	3.16	2.89	3.38	4.42	3.57
Child%	6.16	6.07	6.18	6.72	5.19	6.26	4.24	6.33	7.73	7.20
Female%	30.28	31.27	32.40	32.63	28.39	31.60	30.86	35.46	36.03	38.28
MB%	55.13	54.67	48.54	50.02	52.32	52.20	52.54	51.69	53.42	54.94

Numbers of annual new cases detected nationwide was has remained almost at the same level after 2010 quite stable during the 5 years and the pattern is the same also in our working area with a slight decrease has been observed in the reporting year 2016. In addition, relatively high proportion of child cases and MB (infectious) cases seen in the above table suggest that there is still active transmission going on in the community and provides the ground to anyone to expect more undetected cases in the community. Slight increase in the female patients can suggest that the program has reached more to the periphery with increased access to the females.

A child taking single dose of ripamficin.

Service being provided by NLR supported leprosy referral clinics.

Leprosy Case Detection

The following table gives the glimpse of the national and regional level leprosy control program indicator in our program area, however additional information may be required for micro analysis and future planning. This data corresponds with the national trend provided in the above table.

Region	Population	New Case Detection Rate/100,000 population	Prevalence Rate/ 10,000 population	MB proportion among new	Child proportion among new	Proportion G2D among new
Eastern	61,49,653	11.81	0.94	56.20	5.79	1.93
Farwest	27,82,225	7.48	0.68	70.67	1.92	5.77
National	2,86,24,299	10.67	0.89	54.94	7.20	3.57

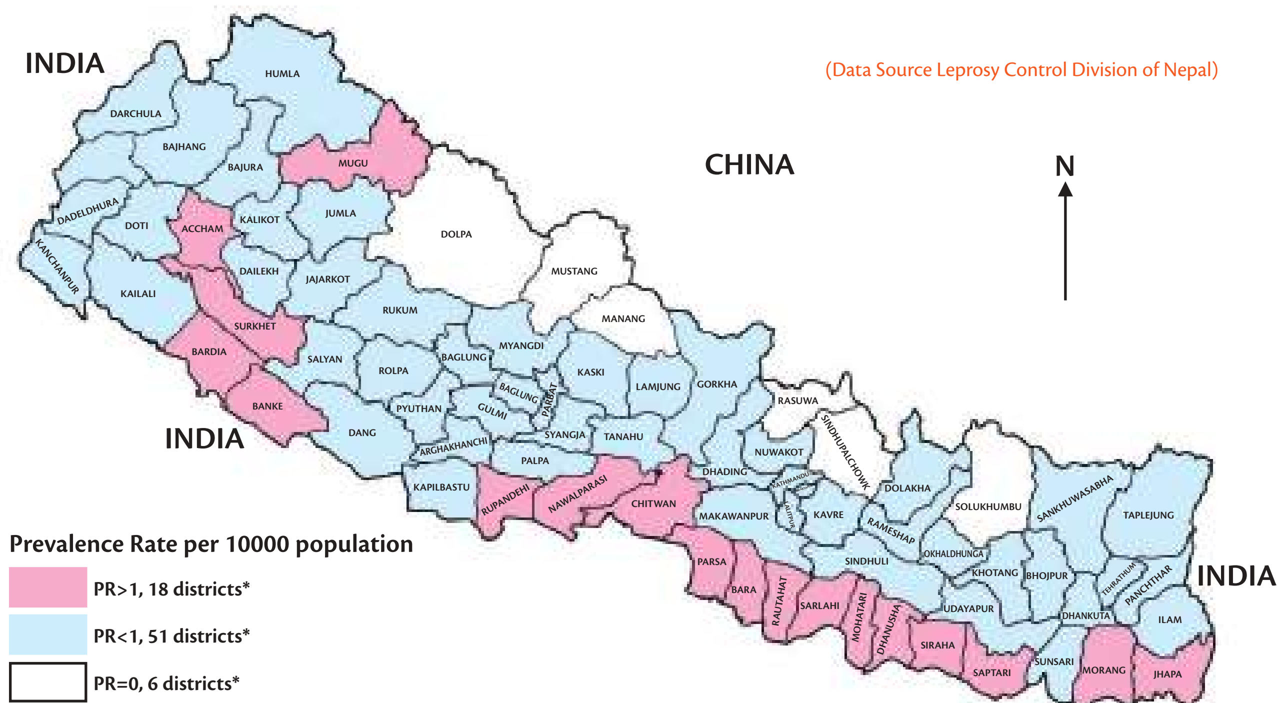
Leprosy Referral Clinic Data of Eastern and Far Western Region

The below contains the data from two zonal hospitals which is functioning well with the support from NLR Nepal. Our support in these hospitals consists of technical expert HR and essential logistics for reactions and complication management in leprosy patients such as anti-reaction drugs, assistive/ protective devices, referrals for surgery etc.

S.No.	Patient Data	Seti Zonal Hospital	Koshi Zonal Hospital	Total
1	Total New Case Detection	69	305	374
2	Child among New cases	2	23	25
3	Grade II Disability	7	23	30
4	Female among new cases	29	129	158
5	Complication Management	287	335	622
5a	Reaction Management	161	85	246
5b	Ulcer Management	126	250	376

5c	Hospital admitted	15	22	37
5d	Surgeries done	10	17	27

Leprosy Endemicity in Different Topographical Regions:



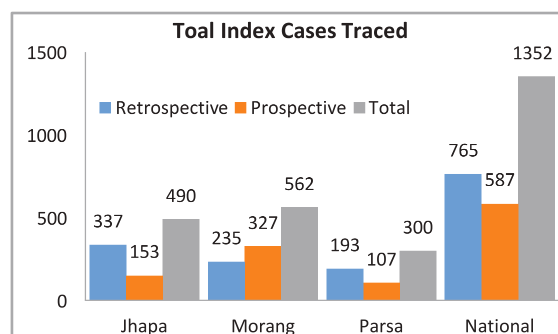
*Districts with PR>1: Accham, Mugu, Surkhet, Bardiya, Banke, Rupandehi, Nawalparasi, Chitwan, Parsa, Bara, Rautahat, Sarlahi, Mahotari, Dhanusha, Siraha, Morang and Japha

As Nepal is divided into three topographical regions, the caseload is almost negligible in 6 mountain districts and lower in 51 hilly districts with Registered Prevalence less than one per 10,000 populations. In 2016 there are 18 districts with Registered Prevalence Rate more than 1 per 10,000 populations. Out of these 5 districts lies in NLR project area and unless an innovative approach is introduced, it is hard to get this figure down. This shows that immediate efficient interventions are necessary in these high endemic districts in order to reduce the burden of disease.

Leprosy Post Exposure Prophylaxis Projet

Based on the trend in case detection especially in endemic countries, an additional tool was felt necessary in reducing the disease burden as there is quite a long way to go with current activities. Because if the evidence of continuing transmission of leprosy, the LPEP project has been formulated with the specific objective as "to reduce the incidence of leprosy in pilot populations of seven countries within 3 years after the start of the pilot projects" with the following assumptions;

- Contact-based strategies is effective
- PEP with SDR effective under trial conditions
- Impact on incidence if implemented in routine programme not known
- Feasibility, acceptability and cost-effectiveness of PEP to be demonstrated



- Initial operational evidence available from pilots in Eastern Indonesia.

The general objective of this project is to demonstrate:

- The impact of post-exposure prophylaxis (PEP) on the incidence of leprosy in a population
- The operational feasibility of PEP under routine programme conditions

A single dose of rifampicin (SDR) is given to contacts of leprosy patients, based on age and body weight (150 mg, 300 mg, 450 mg, 600 mg), through the leprosy control programme in three districts in Nepal with a total population of 2,511,296.

- Total no of index cases approached – 1352
- Number of direct contacts of new patients given single dose rifampicin (SDR) – 31636
- Number of new cases detected during SDR intervention – Leprosy: 158, TB: 20
- Number of people trained by LPEP project till 2016 - Health Worker: 532, Volunteers: 3075

Target groups of this project are contacts (household members, neighbours and social contacts) of leprosy affected persons who were diagnosed since July 2013. SDR distribution to contacts of leprosy patients is done through the routine contact examination programme. SDR is given after complete screening for exclusion criteria such as persons with leprosy or TB, who are <2 year of age, pregnant, have rifampicin allergy, kidney or liver disease.

The main expected outcomes of the project are an assessment of the feasibility on the basis of which guidelines can be formulated on integrating SDR distribution into the routine

Orientation to LPEP stakeholders.

Examination of case of leprosy.

leprosy control programme and a reduction in the number of new leprosy patients detected annually in the intervention districts. The latter is expected to be visible 3 years after the start of the intervention.

At an international level, technical (NLR, Fairmed, ALM and GLRA) and academic Institutions (Swiss Tropical and Public Health Institute and Erasmus Medical Center) partners have been commissioned to support the implementation of the project. The support from Netherlands Leprosy Relief and Erasmus MC to Nepal has included the development of the country specific implementation protocol, support to the training of the staff which is involved in the implementation, and the monitoring of the project.

The Leprosy Control Division has already taking ownership of the project for 3 piloting districts and has started to roll out the approach in five other districts in 2017 making use of the LPEP Strategic Document.

Disability Inclusive Development

Inspire2Care Project

Around 25% of newly born children get some sort of impairment in rural areas of Nepal. Among those, many of them face different types of disabilities. Community people need to be aware about birth related impairment & disabilities. Moreover, persons with disabilities face livelihood hardships as proper disabilities management services are lacking. Socially, persons with disabilities are stigmatized and discriminated which is coupled with feeble implementation of existing policies and provisions at the broader national level. As per the post-2015 agenda and the SDGs' commitment to "leave no one behind", "no goal should be met unless it is met for everyone" including the persons with disabilities

NLR together with Karuna Foundation executes Inspired2Care project focussing on Disability Management and Prevention in Jhapa and Ilam districts of Nepal. Inspire2care is a program that focuses on prevention of childhood disabilities, (birth defects and preventing early impairments from developing into secondary complications) and Community based Rehabilitation of Children/ Adults with disabilities keeping families at centre.

The first one focuses on activities concerning improvement of maternal and child health services i.e. safer motherhood through awareness raising activities, promotion of registration of pregnancy in health institution, pregnancy care

Inclusive Education.

including nutrition, immunization of pregnant women and regular antenatal check-up, delivery planning and institutional delivery, ensuring full immunization coverage of children, nutrition, early management of illnesses, screening at ECD (Early Childhood Development) centres and primary school etc. The second one emphasizes on identifying Children and Adults With Disabilities, carrying out their assessment and develop individual rehabilitation plan ; and providing intervention as per the plan for each child /adult based on the individual assessment. This sets out the medical, social and educational goals of the child and how to achieve them.

The second one focuses on disability management by early detection of impairments and disabilities, preparing rehabilitation plan of each child and adult with disabilities including persons affected by leprosy, provide needed rehabilitation services including socio-economic services through CBR approach by establishing self help groups.

Regarding baseline assessment and rationale of the project districts, the project is implemented in rural areas of Jhapa and Ilam districts of Nepal. Ethnic, linguistic, geographical, socio-economic and cultural diversities are predominant in those communities. Many villages of Ilam and few villages of Jhapa are inaccessible during monsoon. Government structures & framework for health, education & livelihood already exist. There are health institutions & schools in every village with trained health workers & teachers. HFOMC (health facility operation & management committees) and SMC (School Management Committee) are established as governing bodies. Despite of the tangible existence of the regulatory bodies and government infrastructures, the results and developmental indices of health and education among the community are not up to the mark. This project aims to strengthen the existing integrated health system ensuring the pragmatic implementation of disabilities management provisions and also promote inclusive education. The fundamental principle of this program is that in each step of the program implementation government agencies & other stakeholders establish better coordination and allocate equitable resources for health and disability issues to ensure the sustainability of the program.

Meeting with I2C stakeholders.

Towards the Model Villages (OVMV)

Eighty percent of total population in Nepal live in rural areas (CBS estimation of 2016). This number is expected to fall in the coming years, it can still estimated that more than half of populations will be rural even in coming 10-20 years. There are many development parameters showing there is still a significant gap between rural and urban places of Nepal. Health, education, livelihood and other services including sanitation & hygienic behaviour of the rural population is still below standard and due to the stereotyping & traditional practices discrimination and violence are still higher against marginalized populations such as women, persons with disabilities, persons affected by leprosy resulting them as vulnerable groups with low quality of life.

- The project is initiated in 3 VDCs in eastern region and 1 VDC in Far West Region
- The overall objective of the project: Model Villages as an exemplary of inclusive development established

Specific objectives:

- Friendly physical structures
- Comprehensive/disabilities inclusive WASH
- Reduction of the incidence of NTDs and disabilities
- Improved Health, education & livelihood

The "Model Village" concept addresses these challenges comprehensively. It can address resource deficits, attitudinal changes, changes in their practices of total sanitation, empower them on equity & social justice, increase the opportunities on services & livelihood, eliminate the discrimination practices and assist to promote community based inclusive development as "Model" where as Government & others stakeholders will be impressed to replicate to other places.

The project promotes community based inclusive development in 4 rural VDCs of Eastern & Far

WasH Training to Adolescents.

Western Regions of Nepal. With the joint effort of Governmental & Non-Governmental agencies, the project aims to achieve equal access and equal opportunities for persons with disabilities and others in their communities, by reducing barriers for inclusion and ensuring that all entertain equal rights as per existing policies and provisions of the country.

The "Model Village" concept addresses resource deficits, attitudinal changes, changes in practices of total sanitation, empowerment for equity & social justice, increases the opportunities on services & livelihood, eliminates the discrimination practices and assists to promote inclusive development as "Model" for Government & others stakeholders to replicate to other places.

Consultation at Rural Municipality Office.

Disability Inclusive Relief and Rehabilitation (DIRR) Project

The "Disability Inclusive Relief and Rehabilitation", project executed between August 2015 to April 2017 in Nepal. The project has contributed towards more awareness and attention for persons with disabilities and their families in two districts. The project was jointly implemented by Karuna Foundation and Netherlands Leprosy Relief in Nepal.

Urgent needs were immediately addressed. After the immediate relief phase the focus of the project was replaced to reconstruction and rehabilitation. The assessments were done in two project districts and the project was able to treat or manage medical services to persons with disability. A total of 263 family members received emergency shelter support and the provision of assistive devices made by the project eased the lives of persons with disabilities. Likewise the persons with disability or their families benefited from the income generating scheme through the grants, cooperatives and kind replacements.

Support data of Gorkha district implemented by NLR Nepal

- Assessment of persons with disability – 765
- Number of persons supported with temporary shelter – 263
- Number of persons received medical treatment – 232
- Number of persons supported with devices – 58
- Number of persons receiving grant to (re) start a business – 227
- Number of persons trained in disability issues – 315
- Number of persons supported in receiving the disability card - 172

In addition to changes in the lives of individual persons with disabilities and their families, several other notable changes were observed in different categories or groups which have been involved in the project: service providers, rights holders (DPOs), partner organisations and the

cooperatives. The partner organisations working with this project have started to consider disability as an aspect of future interventions. Various service providers (including the VDC Office, health institutions, Women's office) have been sensitized on disability issues during the project.

In order to promote awareness and sensitivity to disability issues among aid organisations and service providers the NLR and KFN organized information sessions and developed an information leaflet on the specific needs of people with disabilities, which was launched at the Human Rights Summit in Kathmandu.

The indirect impact of the project has led to significant increase of the persons with disability (more than 90%) having the ID card in the project area which was below 40% before the implementation of the project. DPOs are established and recognised by the VDC. They played a role to allocate the budget for the disability sector by the VDC. The formation of DPO has given the message to sensitize on disability issues in the community.

Person with Disability Involved in Mushroom Farming.

Disaster Risk Management Workshop.

Disaster Relief and Rehabilitation Project

During the initial relief phase of the Gorkha Earthquake 2015 NLR was involved in providing relief materials to the earthquake hit people of Gorkha including food, shelter, warm clothes and sanitation kits. After this phase, Ministry of Health (MoH) decided to restore and regularize basic health care services in districts highly affected by the devastating earthquake of April 2015. For this, MoH has prepared "Health Sector Recovery Plan." To implement this plan, MoH requested financial, technical, and logistic support from different national and international organizations who have come forward to help the citizens of Nepal in this hour of need. In response to this request like many others, NLR Nepal came forward and signed MoU with MoH to reconstruct the Health Post in Mirkot VDC of Gorkha district so that the people including persons with disability of that area receive quality health care. NLR fulfilled its commitments and the construction of the Health Post is completed. As instructed by the MoH, the Health Post has been handed over to District Health office, Gorkha.

Outcome Mapping

Outcome mapping (OM) is a methodology for planning, monitoring and evaluating development initiatives in order to bring about sustainable social changes.

At the planning stage, the process of outcome mapping helps a project team or program be specific about the actors it intends to target, the changes it hopes to see and the strategies appropriate to achieve these. For ongoing monitoring, OM provides a set of tools to design and gather information on the results of the change process, measured in terms of the changes in behavior, actions or relationships that can be influenced by the team or program.

OM provides a set of tools that can be used stand-alone or in combination with other planning, monitoring and evaluation systems to:

- Identify individuals, groups or organizations with whom project will work directly to influence behavioral change;
- Plan and monitor behavioral change and the strategies to support those changes;
- Monitor internal practices of the project or program to remain effective;

- Create an evaluation framework to examine more precisely a particular issue.

OM is a robust methodology that can be adapted to a wide range of contexts. It enhances team and program understanding of change processes, improves the efficiency of achieving results and promotes realistic and accountable reporting.

OM involves 12 steps in three stages: intentional design, Outcome and performance monitoring and evaluation planning.

NLR Nepal uses the approach of Outcome Mapping as PME tool. All the partners of NLR Nepal are adopting this approach in executing NLR supported projects.

Leprosy Research Initiatives

A. Breaking down barriers: Strategies to include people with physical disabilities, with a specific focus on people with disabilities due to leprosy, in agriculture in Nepal

This research project was thus designed to study/explore the effect of better access to water for agriculture on the wellbeing and inclusion of people with physical disabilities and their families in particular and for all in general. The study/project is strongly focused on 'access of persons with disabilities to water for agriculture' as water remains one of the main 'inputs' for agriculture production and productivity.
The followings key interim observation/results have been obtained through the research:

1. High numbers of persons with disabilities' family members are primarily involved on agriculture in Gorkha (75%) but it is less in Morang (45%).
2. In crop production, unpredictable rainfall is the main problem faced by 96% household respondents which is almost similar in Morang (98%) and Gorkha (95%) followed by lack of irrigation (81%) which is comparatively higher in Gorkha (85%) than Morang (78%).
3. Lack of convenient irrigation supply and technology (82%) is major barriers with respect to disabilities, which is felt by 75% of the respondents in Gorkha and 45% of the respondents in Morang.
4. Lack of promotion on disability friendly agricultural activities and infrastructure (75%), Delay in adoption of technologies with Laggards in communication (75%),

Agriculture Scheme for Persons with Disability Due to Leprosy.

Vegetable Farming Done by Persons with Leprosy Related Disabilities.

Lack of easier work in agriculture (70%), Distance from irrigation water source (70%) are other barriers with respect to disabilities.

5. Regarding physical obstacles/barriers for use of water in agriculture because of disability, lack of availability of irrigation water is the major followed by lack of financial accessibility to irrigation water source.
6. On comparing the scores of participation restriction, persons with disabilities are highly restricted in every domain of life in both the districts. Among the persons affected by leprosy/with disabilities, only 18% felt that there is no participation restriction. General community people other than persons with disabilities have very good satisfaction index for overall quality of life and general health based on WHOQOL.
7. People in general of study area capture rain water for irrigation (66%), sanitation (35%) and livestock watering (34%) using plastic pond and roof water collection. People want access to irrigation through canal, tube well, boring and pipe supply.
8. Lack of awareness, investment fund, commercialization and physical ability etc. are hindering the storage on sufficient rain and surface water for irrigation.
9. Three major ranked strategies for improving access to water are establishment of irrigation canal, construction of underground irrigation system and harvesting and reusing of rain and surface water.
10. About 78% of total respondents believe in increasing inclusion in agriculture with better crop production. This could be feasible through increase gross income and marketable surplus, reduction in cost, self employment, off-farm investment, increased self and social respect etc.
11. Canal irrigation is in practice (90%) for rice farming while maize is rain dependent. For vegetables, tap water is main source of water in Gorkha. Whereas, in Morang rice farming is dependent on either canal (41%), borings (2%) or rainfall (52%). Maize and oilseeds are grown under rain fed situation with few cases under canal irrigation. As vegetables are grown in homestead land, water demand is mostly fulfilled by tube wells or other excess domestic water.
12. Major 3R technologies in practices are harvesting of rain water and surface water, use of farm yard manure and compost, mix cropping, mulching, organic farming, gully control, a forestation, planting wind breaks etc. Though a number of 3R technologies are practicing in both districts, either they are adopting it in traditional way (roof water harvesting, mulching etc) or in some cases without any knowledge (for instance wind breakers).
13. Need to improve access to water common for both districts and establishing irrigation

canal was the common option for both. At the same time, more people in Gorkha indicated that harvesting and reusing rainwater would improve their access to irrigation water while establishing borings and tube wells were the choice to improve water access in Morang.

14. Installation of 3R tools has been carried out in the 4 Pilot sites of 2 project districts. As an immediate result / output of this pilot initiative, it can be noted that selected farmers in the sites and their neighbours (both with and without disabilities) were orientated on 3R technique and practical installation procedure for 3R tools. It is also observed that there is higher level of community collaboration and engagement in such activities.

B. Social exclusion/inclusion and livelihood status of Leprosy affected people in Nepal: A Case Study of Jhapa and Udayapur Districts

The purpose of this study was to study the situation of social exclusion/inclusion of persons affected by leprosy in two districts – Jhapa and Udayapur. Particularly, this study aimed at exploring some of the major socio-economic and cultural barriers that might have hindered leprosy-affected persons' access to health services, rehabilitation, education, employment, livelihood opportunities and to social participation.

Amongst leprosy affected people, are there any differences in access to health services, rehabilitation program, education, employment and livelihood opportunities on the basis of religious, caste/ethnic, gender and geographical regions (Terai versus Hills)? Do leprosy affected persons have enjoyed their rights to choose their partner, to get married, to bear and adopt child and to get parental property.

Short Summary of Results

Livelihood

The largest percentage (67.5%) of the respondents reported that major source of income of thier family was subsistence agriculture and livestock. Though 66.9% people said that they had no difficulties to adopt any kind of livelihood options, only 28.6% (n=78, nearly one third) people were engaged in economic activities. The responses indicated that majority of people 71.4% (n=195) were not involved in any kind of economic activities. Of the total respondents, 33% people said that they had some kind of restrictions to adopt various livelihood options due to leprosy. When cross tabulations were performed, the proportion of females engaged in economic activities was slightly higher 30.9% (n=34) than that of males 27% (n=44) engaged in similar activities.

Discrimination

The present study reveals that 90.6% of the respondents' families took the respondents to the hospital when leprosy was diagnosed. A good thing the study found is that over 70.3% people reported that community behaviors were good towards them when they were recognized as leprosy affected persons. Out of the total respondents, only 21.7% reported that they were discriminated and misbehaved by the family members. When cross tabulations were performed, we found that there was no significant relationship between behaviors and caste, ethnicity and gender.

Regarding reproductive life, 89.2% people reported that they had not experienced any kind of family restrictions on marriage and their reproductive life. We wanted to find out if the respondents had experienced any form of discrimination, only few people (12.4%) reported that they had been discriminated in participating socio-cultural life.

On the contrary to above findings, we found that majority of people (63.6%) did not report their family members about their disease when it was detected. The reasons provided by most of the health workers and community members was that leprosy affected people feel embarrassed and fear that they would get negative responses from the community.

Due to this fear, usually they seek medication from a distant hospital so that they would not be identified by their relatives and friends as leprosy affected persons.

Participation

The result of Participation Scale shows that of the total respondents, over 60% people reported that they did not have any significant participation restriction but only 46% of respondents were affiliated with local NGOs and government organizations, of which, only 15.7% were in leadership positions. Among the respondents who had participated in local NGOs and government organizations, women's participation was slightly higher than men.

This research reveals that there is a significant relationship between participation restrictions and caste/ethnicity and region. Among the caste/ethnicity, over 66% Hill Dalits and 59% Tarai Janajatis had some kind of participation restrictions. Similarly, the restriction levels vary as per the geographical region. For instance, data shows that over 46% people from Tarai district (Jhapa) had some kind of restrictions compared to only 25% in the case of Hill district (Udayapur).

Some of the facts associated are:

- MoU signed with Ministry of Health in July 2015
- A contract agreement has been done with local contractor in December 2015
- The construction has been completed in December 2016
- The cost of the reconstruction project was 5 million Nepalese rupees.

Operational Audit 2016

An Operational Audit done in 2016 through the questionnaire and the documents to which the questionnaire refers, such as the Organizational Manual (OM), came to the conclusion that the Country Office is functioning well. The domestication of OM and updating of some documents such as the Procurement Policy (2008) and the Terms and Conditions of Employment (2006) are still being finalized.

Targeting NLR 2020

As one of the strategies to make functionally as well as financial viable independent NLR country programs by the year 2020, and enable the country program to raise more funds from other international donors besides NLR IO, an Institutional Fundraising (IF) section has been established within NLR Nepal. Currently this was done by the existing staff in addition to their other responsibilities. In the past two years, IF has been successful in the sense that set targets were achieved. As part of the NLR 2020 plan IF will become more important to be more independent in funding from NLR IO. Setting up a local NGO would make local fundraising is also being considered. Developing NLR Nepal website is advised to support IF, communication and possibly local fundraising in the future.

Some Other Highlights of 2016

- International workshop on Disaster Risk Management
- Workshop on Institutional Fundraising and Communication
- Initiation of "Our Village, Model Village" Project
- Initiation of LRI Project
- Set up of Communication and Fundraising Department
- Practice of Outcome Mapping Approach

Partners and Stakeholders

The major stakeholders involved in the NLR program are persons effected by leprosy & their families, persons with disabilities & their families, self-care & self-help groups, community based organizations (CBO), Disabled people organizations (DPOs), CBR organizations, Community consumer groups, Government & non-Governmental organizations. Especially there are strong linkage with NLR between leprosy & disability related organizations but in some cases need based

coordination is made with other sectors such as education & developmental organizations.

NLR is the member of different Networks such as AIN at National & Regional level, NLN at National level, AIN Health Working Group and Disability Working Group at National level, Regional health taskforce at regional level. Further, NLR is frequently invited as a member in some of the event wise networks of education, health & disabilities.

NLR worked with the following boundary partners during the reporting year;

The boundary partners of NLR are Leprosy Control Division of MoH, National Federation of the Disabled Nepal (NFDN), Nepal Leprosy Fellowship (NLF), NNSWA (Nepal National social welfare Association), Progressive Development Forum (PDF), Integrated Rural Development Center (IRDC) Koshi Zonal Hospital (KZH) and Seti Zonal Hospital (SZH) and The Leprosy Mission Nepal (TLMN).

NLR also promotes involvement of other local NGOs, CBOs and DPOs in its works in leprosy as well as disability management.

Management & Administration

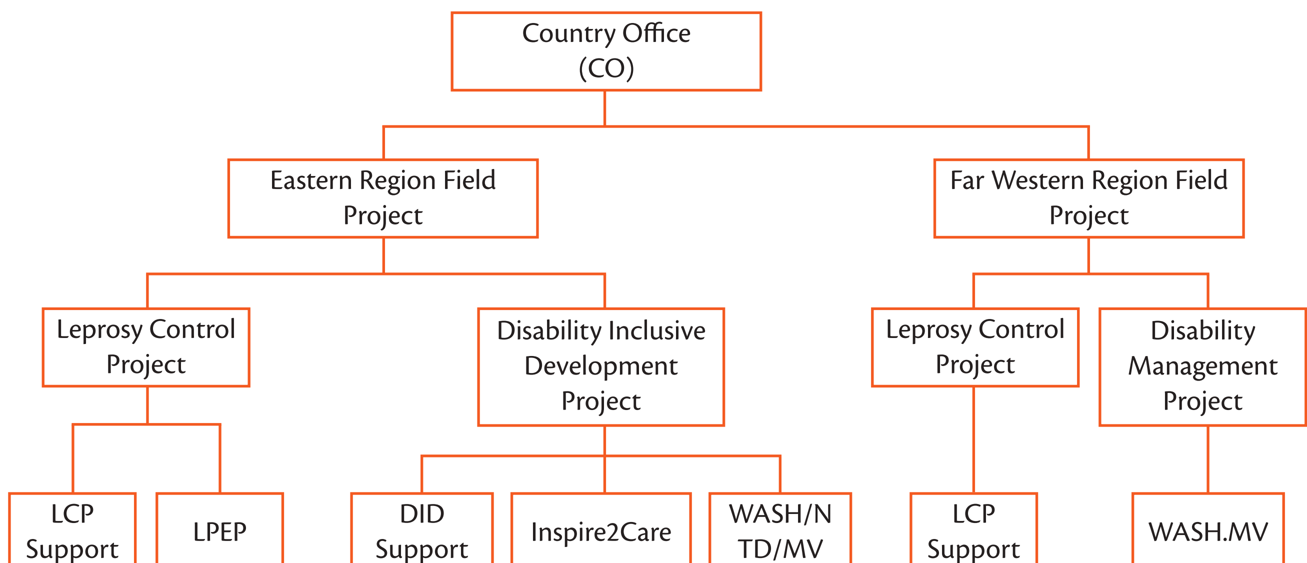
Organisatrional Structure

The country office is led by country Director. NLR Nepal have two field offices one in Biratnagar and other in Dhangadhi.

The coordination and communication among the Government authorities and boundary partners has been continued and NLR Nepal has been able to convince the Government authorities about the Outcome mapping approach and introduce it fully from the year 2016.

The project has run smoothly with the revised structure making the country office stronger and small field offices have been placed in two regions where a team of one leprosy coordinator and one CBR Coordinator and one driver with vehicle are placed. For fundraising and communication work, Resource Mobilization and Communication Officer has been recruited and has been working proactively as a part of NLR 2020 project. The newly recruited staffs are motivated and taking the momentum based on their Job description including implementation the OM approach.

The leprosy referral clinics in Koshi Zonal and Seti Zonal Hospital are running as per their capacity with technical staff support from NLR, although there were some challenges in maintaining quality of service delivery. The recent review showed



a considerable progress in both the clinics. The required training for the staffs was provided by NLR in 2016.

Finance

NLR in Amsterdam is the major donor for NLR in Nepal in the last fiscal year. Besides this Novartis Foundation, Liliane Foundation, SHO and Leprosy Research Initiatives provided funds LPEP, Inspire2Care, DIRR and Researches respectively. The total budget of NLR Nepal in 2016 was NPR 54,609,759 .

(Provide Pie charts showing total budget, program budget, admin budget, and another Pie chart showing different donors contributions)

Case Study

- Name: **Chhukiya Chaudhary**
- Age: 48 years
- Sex: Male
- Address: Baisibichuwa VDC – 5, Kanchanpur
- Number of family members = 7

Mr. Chhukiya Chaudhary says:

"I migrated from Dang district of Mid-west region of Nepal to Simri village of Kanchanpur District when I was 15 years old. I worked as bounded labor in landlord house for 3 years. After that I worked in another person's land as a labor for 14 years in Laurang village of Baisebichuwa Village. During the work, rough hypo pigmented non-itchy patch had been appeared in my right leg and also I had been feeling of tingling sensation in the same leg.

We had bought 3 Kattha of land in Baisibichuwa in 1997 AD and have been living there. Because of increasing and spreading size of patch I visited to traditional healer, he said it is swollen and advised me to locally use powder of chilly on it. I did but it did not work. After few days, I visited another Doctor (Quake) he also said it is swollen and need to take out some impure blood and it will heal. I did and paid NRs. 250 for it, but it did not work, it increased more, instead.

When the patch appeared on my left leg my wife forced me to go health post for the check up. I used to say to her that I have no problem, it does not hurt me and it will recover itself. But when I felt weaker and saw spreading of patches, I went to health post to check up.

After the check up health worker said you have got different type of disease if you do not do treatment in time your legs will worse. I was very afraid. According to him, instantly I went to Leprosy Hospital Dhangadhi. Doctor checked me diagnosed as Leprosy. When I knew about Leprosy, I became very sad and hopeless because I thought; it won't be easily accepted by community people.

Doctor and Nurse counseled me that it is curable disease. It is due to bacteria so full course of regular treatment it will be completely cured and cannot transmit others; it won't be develop

deformity after having treatment. After listening it I got dare and decide to take medicines. I took regular treatment. Finally I completed my treatment and I was saved being worse.

I had problem to walk due to Right foot drop. It is operated and corrected foot drop problem in Seti Zonal Hospital Dhangadhi. Now I can walk without problem. We advise to go health institution to people who are suspected Leprosy. Because of treatment in time, we can save from being worse and we did not have to face stigma in the society.

I am coordinator of self care group and member of Disabled Peoples Organization at Baisibichuwa VDC. We organize meeting once a month and share physical problems. We teach and learn each other to prevent and minimize disabilities and deformities.

I have only a house in small piece of land. I do not have other source of income. So I needed to work in another's land as a labor for the living. 3 years ago, NLR had supported me for grocery shop through DPO. Since I received support, I have been managing our daily expenses from the grocery shop. My family members also help in land-work. Now we are happy. I would like to thank health staff, NLR and other peoples who helped me providing treatment, surgery and Income Generation program."

Case Study 2
From burden to family to a successful businessman

Hari Kumal at Work.

Challenges

My name is Hari Kumal. I am 32 years old man with physical disability due to Poliomyelitis at the age of 7. My both feet are affected and I use my hands for walking and riding my tri-cycle. I live in Peepal tole, Dhangadhi-6 kailali district of Nepal with my wife, two children and unemployed brother. In 2012, I was diagnosed with Leprosy upon examination at NLR run Leprosy Clinic. One of my friends, who was affected by leprosy, had taken me to the clinic. During two years long treatment, I developed reactions which were properly managed in the clinic.

Initiatives

NLR encouraged me to become member of Self-help group formed by NLR .I actively participated in awareness activities in my locality to impart health education for newly detected patients. I used to work as a helper in small tailoring shop in my village. But the income was not sufficient to support my family. Caring for my dedication and huge responsibility towards my family, NLR decided to provide financial support to buy a sewing machine of my own.

Results

With NLR's support, I started my own tailoring shop in my village. As the result of my hard work, I have been able to shift my tailoring shop in city. Now I have three sewing machines with three staff members. I also conduct training in my shop and have trained more than forty people. I have a happy family and have enrolled my daughter in a local English medium school. I now have a handsome amount of income in my account. If I had not got proper treatment and support from NLR, I would have become dependent and burden to my family and community .I am very thankful to NLR for curing me, preventing me from further disabilities and providing seed money to start my own business."

Case study 3
Persons with Disabilities involved in planning

Village Council Meeting.

Challenges

Development works in villages are undertaken in the best interests of the political parties. Such development works which take place on the basis of political sharing and supremacy of political mechanisms have not been able to yield the results expected by people. Political parties decide whether or not people's necessities should be fulfilled. Political parties make major decisions and people take part in the process just for the sake of participation. Moreover, the decisions are not implemented. Political hegemony has become a tradition for years which has cultivated negative impression of development works on community as a whole.

Baisebichuwa VDC of Kanchanpur district, like elsewhere, also faces the same destiny. Political parties and their cadres have remained influential in allocating budget as per their vested interests. Political parties have sheer dominance in ward conferences and village councils. Development budget is allocated based upon political representation and people have no decisive role in the process.

Initiatives

To change the above-mentioned status quo, village development committee of Baise Bichuwa made regular attempts to revitalize Ward Citizens Forum including persons with disabilities and persons affected by leprosy. Consequently, a vision for model village was articulated by the committee of community people dedicated to "Our Village Model Village" campaign. Consultations and interactions were frequently organized for identification and mobilization of resources. NLR Nepal facilitated the process based upon the principle of Outcome Mapping.

Changes

Ward Citizen Forum has assumed proactive role in the community. People are participating in healthy discussions to select and prioritize projects. People are participating in decision making process and taking ownership of development activities. Village development Committee has started allocating budget through project planning meetings. People are committed to transform their village into a model village. This has generated positive vibes towards development works. Development works which take place with people's participation have proven to be more sustainable than the one which is imposed through politics.

Case study 4
Possibilities transforming into credibility

Challenges

Despite of immense potentialities for innovation, the local people of Baisebichuwa VDC were still following traditional norms and practices. Baisebichuwa VDC of Kanchanpur district, adjoining Indian border is full of possibilities for animal husbandry. Nethertheless, prevailing problems like lack of professional skills, lack of pasture land and improper management, unavailability of trained technicians, unavailability of genetic improvement programs, had hindered the progress and development of animal husbandry as prolific occupation. Local farmers were unable to get deserving benefits from this occupation.

Initiatives

"Our village, model village" project commenced its activities in a condition when technicians deployed by district veterinary office were not investing adequate time in the VDC. The project encouraged local level planning to identify and mobilize resources and promoted coordination & collaboration with stakeholders on regular basis. Local people were able to lobby with the district agriculture office to deploy a veterinary technician in the VDC. Technical information sessions were organized regularly. Local people proactively made proper use of the interactions and technical information sessions.

Changes

District veterinary office, Kanchanpur has deployed a veterinary technician in Baisebichuwa VDC under the influence of programme "One village one technician". A breeding center has been established in the VDC for genetic improvement. Veterinary technician provides advices, treatment and technical knowledge to farmers. The number of farmers choosing artificial fertilization is increasing day by day. Farmers and local people are now confident that they can adopt animal husbandry as a lucrative occupation. They expect to develop their VDC as a center for milk production.

Case study 5
Modernization is quite possible in agriculture!

Modernization of agriculture is a widely spoken topic in Nepal. People everywhere relate Nepal with the terminologies like agricultural country, a country with immense agricultural potentials etc. But these beautiful words have seldom translated into reality.

Kanchanpur district which lies in the Terai region of Nepal has a great potential for agriculture. On the contrary, the district faces acute shortage of production despite of possibilities. Government of Nepal has been investing quite a big amount of money for the development of agricultural sector. But the bulky investment has not been able to bring intended results. Farmers still encounter problems such as unavailability of seeds, fertilizers and technicians. Nevertheless, amidst the absence of these basic requirements, farmers of Baisebichuwa VDC have tried to avert the crisis through adoption of modern techniques and utilities.

Initiatives

When services and facilities to be offered by District Agriculture Development office were not available when needed, farmers of Baisebichuwa VDC took the initiatives on their own to adopt modern techniques of agriculture instead of the traditional ones. They have chosen to cultivate off seasonal vegetables professionally.

Famers are associated in different groups and various trainings have been conducted. Technicians are providing services in the VDCs. More than 10 Bighas (Hectares) of land are utilized for vegetable farming. "Our village model village" project contributed to all these developments through a consistent series of planning meetings, resource mobilization interactions and lobbying with relevant stakeholders.

Changes

Agriculture has evolved as an occupation not just a means of subsistence. Every family has an access to proper nutrition and good food. Health and economic condition of local people has improved. Technicians are providing services at their door steps and farmers do not need to commute to district headquarters.

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- Erasmus Medical Center
- National Federation of Disabled Nepal (NFDN)
- Nepal Leprosy Fellowship (NLF)
- The leprosy Mission Nepal (TLMN)
- PDF (Progressive Development Forum)
- IRDC (Integrtaed Rural Development Center)
- Karuna Foundation.

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