CHAPTER I

INTRODUCTION

1.1 Background

Leprosy is known as the oldest disease of the world. The leprosy word in Nepali language is called "*Kustarog*", "*Kode", Kori*", "*Maharog*". Leprosy is infectious disease that has been known since biblical times. In ancient books like the Holy Bible, the Buddhist *Grantha* and the *Shree Swasthani Brata Katha* have mentioned about this disease. It proves that it was from the ancient period of time. The mummies of Egypt found the sign and symptoms of leprosy

Leprosy is highly stigmatized disease in human being. The people's belief on the leprosy is caused of bad wishes of God as a result of misdeed. People thought it is the result of rebirth life; the person had not done well. It is a result of fate or *"Karma ko phal*" or "the law of Karma". The Holy books mentioned this disease as result of bad wishes refusal of taking take of God's *Prasada* (articles of feed offered to the deity). Sometimes religion supported to create negative attitude of people. The result of the traditional attitude, the community and family members behave to them as impure items. It made to breakdown the relationship among family members and isolated them in family and community.

People have lacked of knowledge about the leprosy. It creates fear of transmission and thought it is a very dangerous situation and incurable. They are isolated and kept in a small hut either near to river or in forest because when they will die it will be easy dispose their body or flood can easily sweep away the dead body. Also this word "*kode*" or "*Kori*" are used as a sense of hate.

The leprosy victims are facing social as well as economic problems. They were limiting of participation in social activities and not having opportunities. They were excluded from social and development work. Employer, co-workers and public places have rejected them. Due to disability of leprosy people are unable continue their previous job. It caused them of economic problem for daily life (clothing, fooding, schooling, participation and social function).

They have problems of marriage for themselves as well as their family members. Similarly, divorce and property right problems are found in both sexes. Some of them left their homes without taking any property and migrated to unknown places for work or new settlement. They felt themselves humiliated and no respect from others. It has generated anxiety, fear, depression and isolation. It helped to lose self-esteem and adept negative behaviors. People and family members were not like to contact and behaved with them as either to stay separately or leave the house. Because of the community problems are created to family members. If the PALs stay in village than the bad relationship with other villagers and also may be problem of marriage, work opportunity and freely movement etc.

The family members have been socially rejected for all kind of relationship. The PALs or their family members not allowed to enter others house, spring, well and public places. Due to these events the family members are isolated them for separate eating, washing clothes themselves, and own-self washing plates and keep the plates separately. School didn't accept their children. They have problem to travel in public transports.

The knowledge, attitude and practices have been inherent from generation to generation. The PALs were excluded from own family and own society. The result of society became disintegrated and disharmonious. They have no social security

and loss of self-dignity. The social problems automatically create economic problem. Those PALs have Grade 2 disability having high social as well as economic problems.

People don't know the causes of leprosy and its sign and symptoms. It causes the certain parts of body being senseless (anesthesia). The body parts don't feels, when the body parts pierced with pointed pin or thorn, wood peg, hot and pain; in such conditions they don’t feel of tiredness. The senseless body parts continue to work such as for cooking, farm working, walking and handling tools without taking rest. It causes of blister and wounds. The continuous use the dried parts of body cause of cracking the skin. People don’t care of the wound and become ulcers. Also people don’t go in time to take treatment. And it causes to them deforms their body structure and disability. The deformed body structure looks unusual and it communicates that being leprosy is a very dangerous and deformed.

The Government of Nepal provides treatment at free of cost in all health posts and hospitals for leprosy disease treatment. The plan of government is to reduce the prevalence rate less than 1 case per 10,000 populations of leprosy but it is still higher than the government targeted that is 1.65 per 10,000 populations (2006). The negative attitude of people about the causes of leprosy and practices should have changed after rehabilitation program. However, the government has no specific program of socio-economic rehabilitation. PFR has been supporting different types of activities such as awareness programme, housing, referral, integrated education, income generation and living support for rehabilitation. This study carried out, who has supported on income generation and housing for social and economic rehabilitation. The study on SER effectiveness has been done in very limited cases.

This study is focused to know people are included in social and development work. The PALs have got economic support for income generation and housing for settlement. Similarly, the awareness programs are run at different level to reduce social stigma.

1.2 Statement of the Problem

Leprosy causes of anesthesia, deformity and disability. The government of Nepal has data of the prevalence rate of leprosy but none of them have data about the number of people required SER. Most of the leprosy-affected people were not known with available socio-economic services. The Government of Nepal has no specific programme of SER for leprosy-affected people.

People have less knowledge about the causes of leprosy. The people have adopted traditional attitude about leprosy and relationship towards infected people. The deformity and disability increased the social stigma. Deformity and disability are causes to create fear ness in other non-disabled people to make relationship with the PALs. The result of rejection from other people to make relationship is PALs tries to hide it from others.

The deformity and disability is related with notion of purity. The stereotype, a person-affected is a person *'without hands and feet and with weeping ulcers"*. Ulcers denote a broken skin surface through which impurities can pour forth. The lost of hands and feet implies a lack of completeness. A person lacking in wholeness and completeness is in an inauspicious (*ashubha*) condition. If people meet or see these person during when they are going for start new work or attending very important job, that is not a good time to start or go out *"naramro shait*". It can be a result of failure. There is inter- relationship between social problem and economic problem. Disability and deformity caused to loose their job or got less

work or people didn't use them for their work. Some of them were not able to continued previous job/work. PALs and their family members have several problems such as inclusion for education, fulfill of daily need, freely movement, participation in community activities, respect, opportunity, work, marriage, social relationship and economic etc.

It reduces the level of income due to less opportunity of work. The result of less income is poor health. The rejected PALs from their employer is decreased the income. It affected on poor production. The medicines of leprosy need to take from six months to eighteen months. At the moment of treatment the client has to take rest and eat nutritious food. In some cases the main person infected by leprosy, it creates economic problem for family members. The researcher's study has focused to explore on the impact of socio-economic rehabilitation.

To support above-mentioned statements, here are some points to verify these problems.

a. The government provides medical treatment only, but not mentioned the activities about the social participation.
b. No activities against social action against stigma and de-habilitation.
c. Mostly the poor and marginalized people are victim of economic situation.
d. Nowhere mentioned the number of person's need for rehabilitation.

There are few programs working for people with disabled as Community Based Rehabilitation (CBR). They are getting support from the government of Nepal in some districts. They were not focused programme for leprosy-affected people of SER.

In the Western Development Region of Nepal, the Partnership For Rehabilitation has been implementing SER activities for PALs. There were not sufficient studies done against the impact of socio-economic rehabilitation. This type of study is necessary to explore the impacts of SER. The researcher found Ulla-Britt Engelbrektsson who did a study for a few individual cases of Mid-western and Western region in Nepal (2001). The researcher found that most of the people said social stigma has no longer in the case of leprosy clients. The researcher verified that about changes of attitude and practices of family and community in different levels. PFR has provided awareness programme, it is not sufficient to reduce the social stigma. Do PALs feel it a social stigma? Until changing the social context, the economic context is not being certain. At below mentioned questions will support to find out the impact of socio-economic rehabilitation aspects. In this study focused on the following key questions:

1. What type of relationship has among the family members with leprosy clients?
2. What are the income sources of clients?
3. What is current situation of given support by PFR?
4. Are they included in mainstream of development activities or social participation?
5. What are their perceptions about the causes of leprosy?
6. What do they feel when non-leprosy people sit together?
7. How could be the rehabilitation successful?

1.3 Objectives of the Study

The general objective of the study is "To understand the socio-economic status of the people affected by leprosy after socio-economic rehabilitation in the Western Development Region of Nepal".

The specific objectives of this study are as follows:

- To prepare a socio-demographic profile of respondents.

- To know the effectiveness of socio-economic rehabilitation services for PALs.
- To gain knowledge and contribute about the concept of social and economic rehabilitation.

1.4 Significance of the Study

Lacking of knowledge about leprosy is the cause of disintegrating the society. All people of a community should be included in the mainstream of development activities. The behavior or human being is guided by level of knowledge. It is important to know the current situation of PALs and their family after rehabilitation. Do community and family members accept them? Is the life easy to get employment opportunity? This study will explore the changed behavior and practices.

This study will guide the organization to make a good plan. The current policies and strategies are needed to revise or not. Because there are little study done about impact of SER. This study will support to develop an effective strategy for rehabilitation. The part of evaluation is most necessary to review the strategy, monitor the program and to know the cost effectiveness. Evaluation can be mid term of the project, end of the project and after few years of completion to know the sustainability of the project.

The researcher has been working in socio-economic rehabilitation field in Partnership For Rehabilitation. The findings will help to look deeply about impact of SER. The researcher will use the knowledge at the time of planning and making strategy. The findings will be shared in a rehabilitation team for further actions. Also this study will broaden the knowledge how to carry on a good research. The researcher can guide local NGOs to include PALs issues in their program. The depth of searching will help to find different publications and useful findings to increase knowledge.

Thus, the study has an importance to understand the socio-economic changes of PALs life after socio-economic rehabilitation. It is thought to be helpful to planners to make strategy and planning at micro level to improve socio-economic situation of clients.

This study will help to understand the following:

- participation in social activities
- understand the improvement economic status of PALs
- different good ways of rehabilitation

1.5 Limitation of the Study

This study is focused to know the socio-economic changes of clients after rehabilitation in people affected by leprosy. PFR has supported 177 clients for income generation and housing. All the supported clients will not represent as respondents due to shortage of time, limited budget, changing political situation, and vague geographical area and other different types of barriers. Some limitations are as follows: such as

- The conclusion of this study may not be generalized with other types of disease and rehabilitation works. Because leprosy is a stigmatize disease, having multiple problems. So that the rehabilitation process may not resemble to other kind of disease.
- There were carried out few studies in socio-economic rehabilitation of leprosy-affected people (Sociological/Anthropological views). It may be difficult to get similar type of literature or documents in the Nepali context.
- The rehabilitated client may die or migrate in other places for the sake of food, work and social security.

- The study may not represent whole society of Nepal because it may differ according to different ethnic groups, the caste wise, belief and different level of education and available of facilities.

1.6 Organization of the Study

The researcher included seven chapters in this thesis. The first chapter explains a brief explanation of the background, problem and objectives of the study. In addition, the significance included the importance of this study. The second chapter presents about related literature related publications in Nepal and world.

The third chapter explains about the research methodology. The data analysis is the statistical processing programs. The presentation of data in the form frequency, percentage, graphs and tables. It also includes the conceptual framework of the socio-economic rehabilitation in diagram.

The chapter four presents the physical setting of the study area and demographic profile of the respondents. Chapter five explains the relationship between leprosy-affected people and social relationship, acceptance in family and community about in social activities, changed attitude of community peoples about leprosy and feelings of respondents of community people acceptance.

Chapter six explains the relationship between leprosy and economic rehabilitation. Different types of income generation activities supported to clients such as provision shop, agricultural and livestock business, vocational training with business etc. The area of improved in other areas and suggested good ways of SER. Also included are the views of key informants and interviewer about the current situation of the client. The last chapter seven includes the researcher summary, conclusion and recommendations.

CHAPTER II

LITERATURE REVIEW

2.1 Theoretical Overview

This chapter presents a literature review based on the research problem.

2.1.1 Leprosy in Historical Perspective

2.1.1.1 World

Leprosy is known as the oldest disease in the world. Also it is one of the highly stigmatize disease. Leprosy was found in the pyramids and mummies of Egypt. So that it proves that it is a disease known in ancient times. The mummies were about 2400 B.C. The holy Bible mentioned the word “leprosy”. This word “Leprosy” translated the Hebrew word “Saarath”. The Saarath word was included a number of skin diseases and not leprosy alone”. (R.H. Thangaraj, 1975).

The leprosy disease entered just before the Christian era. In China, it was considered an ancient disease before 600 B.C. In ancient Chinese literature, one comes across Tang Fung Tzu (chalmoogra oil), which was used for the treatment of Tang Fung (leprosy). In Japan, the Japanese data from the last 400 B.C. indicated a wide dissemination of leprosy in historic times (V.N. Sehgal, 1970).

In the American continent leprosy was entered by the Columbus soldiers first and later through slave trade from endemic areas in the West Africa. There are large foci of leprosy in South American countries and in states like Argentina, Brazil and Columbia, it stills posses serious public health problem. In India, leprosy is mentioned as “Kushtha” in the ancient Vedic writings as far as back as 1400 B.C.

Leprosy situation by WHO regions (1998 October) shows that the South East Asia is highest number of new cases detected (5, 69,875) and lowest is Europe (37) (WHO 2 October 1998, No. 73, 40). Similarly, there were highly endemic 16 countries. Nepal was in 9th position of the worldwide. In Nepal, prevalence rate was 12,540 and its rate was 5.30 per ten thousand populations (WHO report 1998). In Nepal between 1992 and 2005, the number of leprosy prevalence cases and new leprosy cases detection rate decreased by 72.4 and 23.6 percent respectively. It indicates that the rate of leprosy prevalence rate is decreasing continuously.

The social stigma is high in rural, poor and illiterate communities. Rural area has high social stigma compare to urban areas. Because people are illiterate in rural areas and beliefs on traditional practices, the attitude of people is highly affected by religious factors. It is believed that leprosy is caused by God's punishment. The punishment is so fearful that body structure looks like very unusual; deformed face with loss of hands fingers and toes of feet. A study found in India that "stigmatising attitudes were associated with lower educational level, lower socio-economic status, female gender, and the Muslim religion".

Most of the leprosy treatment centers are running to focus the medical treatment for leprosy disease as isolated program. It is causing of creating negative attitude of people. It is only for those people who are diagnosed as leprosy patients. Kaplan suggested that "…….. biblical writings concerning leprosy should be interpreted as general skin diseases".

People believe it is a genetic disease and it transfer from generation to generation. Those patients who have leprosy than it transfer from parents to their offspring. The spoiled gene of parents is affected by leprosy than it will affect in offspring. Leprosy is caused by bacteria and not transfers by gene. O.K., Skinsnes (1964) *The Chinese believed that leprosy is sexually transmitted by contact with a prostitute*

and hence a punishment for immoral behaviour. The belief about hereditary of leprosy is prevalent among communities in China.

There are very few programs that have supported for socio-economic activities. The Grade 2 PALs need socio-economic support to reduce social stigma. The leprosy-affected people don't get the existing benefits for socio-economic rehabilitation services. Gopal (1995) states that there were approximately 6000 PALs in the Western and Mid-western development region of Nepal. Estimated cumulative release from treatment cases (RFT) of the same period was 60644. The estimated population 10 percent (6000) of total RFT was needed of SER. The SER is the major part of the leprosy programme. Also the recommended 4500 PALs were not accessed to SER services. There were lacks of accessible services and lack of expertise with proper guidelines.

The society structure is not appropriate to people with disabled. Society is failed to arrange the required demand and structure for the disabled people. Most of the family and community people attitude that the PWDs are not able to do any kind of contribution in household and in community. Harlen Hahn (1986),“ ……. writing within the North American context, states that disability stems from "the failure of a structured social environment to adjust to the needs and aspirations of citizens with disabilities rather than from the inability of the disabled individual to adapt to the demands of society".

Poverty is also one of the major causes of the disability. Social and economic rehabilitation aims at social integration, equal opportunities and economic advancement for PALs and PWDs. The United Nation standard rules for Equalization of Opportunities for Persons with Disabilities defines “Rehabilitation includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of

life and self-actualization". In the rehabilitation process-addressing poverty is an essential part of rehabilitation.

The First National workshop on Leprosy Control was held in Kathmandu on 20-24 February 1979. Dr. R.H. Thangaraj, Secretary of Southern Asia, The Leprosy Mission, India presented a paper about "Diagnosis and classification of leprosy". He mentioned, one thing, which greatly affects the spread of leprosy, is the socio-economic conditions. This is a great factor and we cannot ignore this whatever we do. Unless we improve our socio-economic conditions, we will never be able to eradicate leprosy. One thing they did in the eradication programme in the West is that as their socio-economic conditions improved leprosy disappeared (HMG/WHO 1979).

2.1.1.2 Nepal

In Nepal, the socio-economic rehabilitation works has done in limited areas through INGOs. During the Rana regime, no leprosy patient was allowed to enter in the Kathmandu valley. None of the Government cares the patient seen in the street or around the temple for begging at poor condition. The government of Nepal opened a leprosarium in Khokana and Syangja district of the Western Development Region of Nepal. The Khokana leprosarium management has been handed over to Nepal Leprosy Relief Association, under the Handicapped Social services Coordination Committee. The improvement of the living conditions of patients and to make them fit for rehabilitation in normal social life outside the leprosarium, it was imperative to formulate an operational plan for the leprosarium.

In a study on community behavior in Eastern Nepal towards leprosy affected people, de Stigter et al. shows that persons affected by leprosy tried to hide their disease out of fear for negative community behaviour (stigma). They state that

'persons affected by leprosy experience exclusion from social life…. they have difficulties in gaining employment or they are refused jobs. In general, persons affected by leprosy experience unsympathetic reactions, insults, hate, abandonment or rejection…." They go on to indicate that the motive for such negative community behaviour is a "fear of infection by germs", as well as "fear of a curse of God.

The Institution Based Rehabilitation (IBR) is a strategy to keep PALs isolate them form their family members and only concentrating them in leprosarium. The IBR strategy was changed into rehabilitation with there own family and in own community. It is a sustainable and their rights to live with their family members. The plan was given more focused to change the attitude of people towards the leprosy clients to inclusion in their own family and community. This would help in achieving the aim of the plan of SER to rehabilitate the patients in their own families or elsewhere. In addition, in the context of Nepalese socio-cultural values, it is important to have some vocational training centers in the form of earning something for their maintenance.

The Nepal Leprosy program's National policies (2001).

- The leprosy is the public health problem and having planning to reduce at the end of 2005. It means less than 1 at per 10000 populations.
- To identify the disease at initial stages and start multi drug treatment to prevent disability and impairment.
- To provide integrated health services to all populations through primary health services. To provide training to all health workers through multi drug treatment services.
- To raise awareness in community about misconception of leprosy and its treatment.

In Nepali context, the fear of social stigma is caused of hiding about their disease. Most of the people have no knowledge about the sign and symptoms of leprosy. Some people refused to accept her-self or him-self as leprosy affected. They don't want to go in hospital for health check up. Similarly, pure and impure are related with physical disability. Physical disabled is an incomplete person that is not accepted as priest because of impure. The God won't be happy. Khawas, Ishwor Bahadur, Leprosy and Social Stigma (2000)

> " ……. Out of 40 general public respondents more than 42 percent had no any idea about the early signs of the disease." Lacking of knowledge was the causes of social stigma. Another data described that "People affected by leprosy may be accused as 'impure' and may be restricted for religious performances. The 'impure' because of a belief that people will be affected by leprosy as a result of sin/bad work one's past life."

The target of the Government of Nepal is to decrease the prevalence rate less than 1 case per 10,000 populations by the end of 2005 A. D. In this study the prevalence rate of leprosy in five districts is higher than the targeted i.e. Rupandehi (1.98), Kapilbastu (1.89), Chitwan (1.88), Nawalparashi (1.83) and Kaski (1.07). Manang is only one district where the prevalence is zero. There are 11 districts, which prevalence rate is one or less than one (F/Y 2062/63).

The statistics of last four years the prevalence rate of leprosy is decreasing. In 2002/03, 2003/04, 2004/05 and 2005/06 the prevalence rates were decreasing 3.04, 2.41, 2.02 and 1.65. In addition, the prevalence rate of the WDR is 1.14. Still the prevalence rate is higher than the elimination target. Nepal has witnessed a declining trend in both the leprosy prevalence rate and the new case detection rate. The prevalence rate stood at 1.82 (Ojha, Bimala, Ministry of health, (Nepal Source: For the Elimination of leprosy, August 2006, Number 21).

2.1.2 Medical Perspective

The alternate name of leprosy is called Hansen's disease. Norwegian, Doctor Garhard Armour Hansen first time identified it in 1873. Leprosy is a chronic infectious disease caused by bacteria. The organism Mycobacterium leprae causes leprosy. It has long incubation period and less chance of transmission. Leprosy is characterized by disfiguring skin sores, peripheral nerve damage, and progressive debilitation. Leprosy has two common forms, tuberculoid and lepromatous. Both forms produce on the skin, but the lepromatous form is most severe producing large, disfiguring nodules (lumps and bumps).

Both forms of the disease cause peripheral neurological damage (arms and legs). It causes sensory loss in the skin and muscle weakness. Damage of peripheral nerves causes loss of sensory, motor and autonomic nerve function to the affected region, leading in turn to deformity, secondary deformity resulting from repeated trauma as well as dryness and cracking of the skin. Bacteria primarily affect peripheral nerves, skin, eyes and mucous of the upper respiratory tract. Sensory function loss is a cause of repeated injury, ulceration and limb shortening. Corneal sensation loss may result in unrecognized corneal injury and significant visual loss. Motor function loss is a cause of finger and toe clawing, failure of eye closure (logophthalmos), and foot and wrist drop.

Leprosy can occur at all ages but sensitive age is from 10 to 20 years (WHO 1988). In 1988 WHO definition is “a case of leprosy is a person having clinical signs of leprosy, with or without bacteriological confirmation of the diagnosis, and requiring chemotherapy” (WHO 1988, p. 23).

Leprosy affects on sensory functions. The cause of frequent injury, ulceration and ultimately loss of body parts. That person affected in peripheral nerves and frequent ulceration is not be able to do regular works. It leads to problem of economic and participation; continue social problems. Leprosy is more medico-social problem rather than a disease and that the social aspects in terms of stigma, discrimination, poverty, deformity and loss of self-confidence are still need to be overcome. Due to leprosy, the person facing problems like segregation, negative behavior, break down of relationship, limitation and restrictions in many social functions.

2.1.2.1 Ways of Leprosy Transmission

All people have own immunity power to prevent to infection of different diseases. The immunity power destroys the bacteria. Most of the study shows 95 percent populations have immunity power to prevent infection of leprosy bacteria. It is transmitted only those from those people, who have not taken medicine, if they sneeze, respire than the bacteria come out. Those people who have low immunity power easily transmit in their body. Also, those houses have not well ventilation and stay very close to each other for a long period of time, it is a good environment for susceptible the bacteria. The person with mal nutrition can easily transmit in their body.

2.1.2.2 Signs and Symptoms of Leprosy

Leprosy sign and symptoms can be seen in skin and nerve system of different body parts. Leprosy is diagnosed on the basis of clinical signs and symptoms but to confirm laboratory tests is compulsory. WHO recommended that an individual should be regarded as having leprosy if one or more of the following signs and symptoms are shown:

- Hypo-pigmented or erythematous skin lesions with loss of sensation.

- Involvement of the peripheral nerves demonstrated by thickening and sensory loss.
- The presence of Mycobacterium leprae in skin smear (WHO 1997 c).

The skin becomes red or dried without itching, sweating but sensory-less. The mouth face skin and lower parts of ear thickening and shining symptoms can be observed. Nodules in face and other parts of body, losses of eyebrow, Ulcer can be seen in palm of hands and lower part of feet. If any two signs are seen in a person one can guess about leprosy.

These skin lesions may be anesthetic or have normal sensibility. Nerve lesions occur in dermal nerves as well as in superficial sensory nerves and nerve trunks. One or more nerves may be enlarged on palpation.

Secondary signs such as clawing of fingers and toes, absorption of digits due to repeated injury and dry skin are due to impairment of motor, sensory and autonomic nerve function.

2.1.2.3 Classification of Leprosy

WHO classified leprosy into two types. It is based on the probable number of *Mycobacetrium leprae.*

- Pauci-bacillary (PB)- The bacteria present only very few number of bacilli. PB group comprises of the Ridley-Jopling group II (Intermediate), TT (Tuberculoid type) and BT (Borderline tuberculoid). In this type of bacteria, signs and symptoms one to five senseless spots can be observed in different body parts.
- Multi-bacillary (MB)- Number of bacteria in large in numbers. The sign and symptoms can be seen more than five patches on body of the person. The MB

group consists the Ridley-Jopling categories BB (Borderline), BL (Borderline lepromatous) and LL (Lepromatous) types of leprosy

2.1.2.4 Disability and Impairment Grading

Hands, feet and eyes:

0- Grade Normal eye, hands and feet (not affected by leprosy)

1- Grade Loss of sensation but no visible deformity. Lagopthalmus on eye but vision power 6/60 or better

2- Grade Visible deformity on hands and feet, but eye affected by leprosy and vision power less than 6/60

Source: National Manual of Leprosy Control Programme-2nd Edition 1997

2.1.2.5 Treatment of Leprosy

In the ancient time, there were no proper treatments of Leprosy. They treated what they know and also contact with traditional healers. They used their knowledge to prevent spread of disease. They isolated the leprosy patient out of their community; it might be to protect them to spread the disease. Today, leprosy treatment is available from all health clinics at free of cost.

First time, the medicine of leprosy Dapsone was introduced in 1956. In 1980, new medicine Multi Drug Therapy was found for effective treatment of leprosy. The recommended dose mentioned in table 2.4.

Table: 2.1

Recommended by WHO MDT Regimens for Adults

PB single-lesion leprosy	**PB leprosy**	**MB leprosy**
Rifampicin: 600 mg. single dose	Rifampicin: 600 mg. Once a month	Rifampicin: 600 mg. Once a month
Ofloxacin: 400 mg. single dose	Dapsone: 100 mg. Daily	Dapsone: 100 mg. Daily
Minocycline: 100 mg. single dose		Clofazimine: 300 mg. Once a month & 50 mg. daily
Duration: only once	Duration: 6 months	Duration: 12 months

Source: Adapted from WHO, 1997b

2.1.3 Social Perspective

Leprosy has always considered as “Maharog” (biggest disease) with dangerous fearful structure. It defined as result of bad work in past birth or result of sin. In Hindu religion it is considered that, leprosy is a cause of divine punishment, evil eye, result of past work, curse, sin etc. Some people believe it is cause of bad blood or heredity. The cause of leprosy is not known it is presumed to be divine punishment or result of sinful living in the present or past birth. Therefore, they do not like to touch leprosy people and isolate from the family and society. None of community or family members like to be close sharing. Either person self or family members or community people isolate to them from their house/community. Leprosy causes big social problems in people for leprosy-affected people and their

family members. The people believe that it is fate of an individual to be a leper. Dor Bahadur Bista (1992)

> "The popular belief, supported by the priests is the on sixth night, bhaavi, the dem God of providence, comes to the house to write the fate of the child on it forehead. Thereafter one life is guided at all times by the writing of bhaavi (God) and it is not possible to really alter one's bhagya (fate) by any dead unless it is of a ritualistic kind aimed at affecting powerful supernatural forces".

The stigmatized disease leprosy is affected in human society. The stigma of leprosy has relationship with religion. Physical beauty is also one of the qualities of God, which is adorned by humans. Physical beauty amongst people is appreciated as the gift of God. Clearly, deformity in leprosy would be considered as divine punishment. Mutakar (1979) states

> " A leprosy patient is always a deformed person in the eyes of lay people. They remember having seen the person as normal and fail to understand the process, which has made him, deformed. In the absence of knowledge of causation and cure of leprosy people blame the afflicted person himself for deformity.

Most of the family when someone gets sick than almost all-family members involved to care the sick person. Than, the family members give care, love and provide nutritious food. But when a person gets leprosy, the family tries to escape as a member of the family. At this time the family become worry and thinks about the relationship with relatives, neighbours and community people. The family isolates them in kitchen, bedroom and separate eating plates. The children are allowed to play together but worry about marriage of the children. The society member is denied at any place in the society. The leprosy person becomes a non-person. The relationship has broken down between husband and wife, daughter-in-law /son-in-law with parent-in law. He/she suddenly loses his/her ascribed status of fatherhood, motherhood, brotherhood etc. The leprosy person also loses

achieved position at the place of his/her work or in society. The status accorded to him is that of social death, a status that has no roles to perform in society. Even the position is high in caste system get down in the same caste. Such as the Brahmin patient equally rejects an untouchable leprosy patient. Deepak S, Gopal P K, Husch E. (2000) state that," …… even today, social stigmatisation is frequent so that affected persons with clear signs of chronic manifestations are often unable to work, or to marry, they become dependent for care and financial support, leading to insecurity, shame, isolation and consequent economic loss."

Most of the daily wages or regular workers PALs remains fear because of loose their job. If the owner or friends are aware about their disease than may lose job. While Scott in his study the psychosocial needs of leprosy patients in South Africa, discovered that all of the subjects were afraid of losing their work, and 17 out of 30 did not mention the name of their disease to their employers.

Kaur and Van Brakel (2002), in their study of leprosy-affected beggars in India, point out that they have found that the combination of leprosy, physical impairments and social stigma leads to 'de-habilitation' of the leprosy affected person, which ends with the person becoming a beggar. De-habilitation in this context is defined as loss of former place in society or social role, causing loss of dignity, job and/or position leading to physical displacement. The social stigma leads to no job or work and limited to participate in social activities. It is discourage to stay in family and own community and remain only one option for begging to survive and migrate to another places.

The PALs live in extreme poverty and have few opportunities to earn an income. They may be excluded from their former work place or denied access to their former market. They go on to state that the physical impact of leprosy may take it impossible to continue in their former occupation. This is a point that is extremely

relevant, it is not simply a matter of stigma being the sole cause of income loss, and there are complicating factors involved.

Mee Lian Wong, (2004) research has shown that it is difficult to change people's attitudes and that high knowledge of the curability and non-infectiousness of leprosy did not necessarily lead to more positive attitudes towards persons affected by leprosy. This could be because beliefs about the bad origin of leprosy are so deeply rooted in people's culture that a simplistic approach of just presenting the scientific facts may be ineffective in addressing their concerns and beliefs.

More holistic multi-component programme is needed to address stigma, with interventions targeting individual, interpersonal, health system, and community and policy levels. Discriminatory attitudes of the health personal should be addressed. A well planned needs assessment will also help in designing more appropriate health education strategies and more specific and relevant messages that relate to the community's concerns.

The most important thing is to aware the people about the causes and it's treatment. There are different sources of media to aware people but the effectiveness may differ. Leprosy Evaluation and Monitoring reports a total of 111 community members living across 10 districts of Nepal and all the five regions of the country were interviewed aged between 15-60 (95%). Majority 79% was aware of the availability of treatment for leprosy. And 78.4 percent believe that leprosy is curable. Coverage of TV 40.5 %, radio 29% and very poor through reading newspaper. The cause of leprosy and the signs and symptoms didn’t know by 36%. The 78.4 percent believed that leprosy is curable.

Female is more vulnerable stage than male. Female PALs have lots of social problem in family as well as in community. Vlassoff, C. et al. (1996) has mentioned that, Female will faced more difficulties than male. Because feeling of male and female is not equal. Male is more than female, they think that if wife will get leprosy then he could get another wife easily, but female cannot get another husband easily. Yet male can earn and there is much option for them but for female after marriage there is no other choice. The visible disability and deformity has greater chance of rejection rather than invisible people infected by leprosy.

2.1.3.1 Social Model

Social model is related with harmony in society. People think that leprosy disease creates disharmony in society. This model focuses to the detrimental and oppressive structure of society. It does not analyze the functional, physiological and cognitive abilities of the impaired individual.

J.E. Hyland (1993) has described that leprosy is curable (*kushtharog niko Huncha*) is thus somewhat misleading to ordinary people and contradiction in terms. In particular it is not believed when the person said to have been cured is a leprosy patient (*kustharogi*) who has completed the necessary treatment but who still has deformity and specially has ulcers. They still have *kustharog*. Neither is there a concept of social cure for the socially separated or exposed *kustharogi* in traditional Nepali society even when declared 'medically cured'. It means we can say that leprosy is that type of disease, which destroys not only the body, but the soul of human being also.

Leprosy is cured medically but who has disability and deformity suffers big problem of rejection from family and society. In some cases, a long time ago death of leprosy patient's remains some negative social residues in society. WHO, 1998

defined the disease has afflicted humanity for a long time. It once affected every continent and it has left behind a terrifying image in history and human memory of mutilation, rejection and exclusion from society. Since ancient times many communities have regarded leprosy as contagious, mutilating and incurable.

The belief of social model is that, irrespective of the political, economic and religious character of the society in which they live, disabled people are subject to oppression and negative social attitudes that inevitably undermine their person-hood and status of full citizenship. Central to the notion that disabled people are oppressed is the underlying assumption that all societies are characterized by conflict between two competing groups; the dominant and the subordinate.

Finklestein, (1980) concluded that history can be divided into three phases and that within each phase the manner in which disabled people were socially included or excluded within society. First, agrarian feudalism and some cottage industries characterized the period before the European industrial revolution. There was scant social mobility, where it is maintained that the mode of production did not exclude disabled people from active participation in their local communities. The second phase, the industrial revolution and its immediate aftermath, disabled people were effectively excluded from being in paid employment, due to the fact that they were not able to maintain the pace set by the factory system. As a consequence, disabled people were separated and socially excluded from mainstream social and economic activity. The result of people with disabled become marginalisation. Disabled people have become further isolated through their family. The third phase, which is just commencing, disabled people will witness and experience their liberation from social oppression. There were established of Institution based rehabilitation as closed and segregated institutions, for example, within many so-called "special

schools", and sheltered training workshops. Social model specially focused the rehabilitation activities in own society of client.

2.1.4 Sociological and Anthropological Perspective

Change is a continuous process in all society. Everywhere due to natural, political, social, economical and technological change affects on every society and every level won't remain change. Change is also related with knowledge, attitude and practices. Socio-economic rehabilitation changes the knowledge, attitude and behavioral practices of family and community.

Bettie (1964) described about change is an inseparable entity of society at any time. Change can be sudden and catastrophic, as when a system of government is destroyed by revolution and placed by different one, sometimes it is gradual and hardly perceptible, so that even the members of society themselves scarcely notice it.

Gardener and Lewis (1996) “In "Division of labour 1893", for instance, Durkheim-who is widely considered out of the founding fathers of sociology compared "primitive and modern society" being based on the model analogue to organic evolution. The former society, he suggested, has 'mechanical solidarity', in which there is no division of labour, a segmentary structure and strong collective consciousness. In contrast, modern society exhibits 'organic solidarity'. These involve a greater interdependence between component parts and highly specialized division of labour production involves many different tasks, performed by different people. In such social structure is differentiates and there is a high level of individual consciousness.

In Nepal, from 1961 had started government a planned development activity is called five-year plan. Some changes such, as from the government level, was planned and systematic transformation of society where as some others changes were unplanned and violent. In the period, the word 'development' has become popular. Some changes are carried out in the name of development (10^{th} five-year plan).

Social development is the change in attitude, knowledge and practices. Social development is a process of planned social change designed to promote the well being of the population as a whole in conjunction with a dynamic process of economic development. Each and every time change is a continue process. Social change is a modification in ways of doing and thinking of people. It is also related with change in human relationship.

Ghimire, Madhav (2002) in his study, the relationship between secondary deformity and other variables, no significant differences were found except in relation to the age group. The existing notion that rural people have higher chances of developing secondary deformity is not supported in this study where three fourths of urban residents had secondary deformities while only fifty percent of rural residents had secondary deformities. However, in the study the difference in the proportion of these three variables (education, economy and occupation) and secondary deformities are not significant possibly because of the small sample. But it is seen that there is a trend towards a possible relationship between secondary deformity and educational, economical and occupational status. The findings suggest that if people are from a lower educational and economic status, they have more chances of developing secondary deformities. Similarly, the secondary deformity is higher in manual workers compared to the non-manual worker.

Social change is an essential law of nature; it is continuous process and cannot be predicted. The number of factors is the result of change. Sometime a factor is sufficient for change and sometime need of group action for change.

Calcraft J.H. (2006) mentioned in his study there were several cases where stigma did indeed account for a decreased income. Although this was not true in all cases, sufficient evidence was discovered to show that this is a current problem faced by people affected by leprosy in Nepal. Where a stigma related problem was present, the consequences for the person affected by leprosy, were extremely negative. The greater effect of leprosy on income generation was found to be from the physical effects that often come with the disease. In the majority of cases, there is a definite loss in income, and in income generating ability of the interviewees, or of their leprosy affected family member.

The leprosy affected person or their family members don't accept by his/her community than they needs of socio-economic rehabilitation. When the limitation of work opportunity than the result gets poverty. The physical disability and leprosy limits the participation of social, economic, education, cultural and community. The PALs health situation become continues worse and he/she might be rejected from family and community. The result of rejection leads for begging, social insecurity, and psychological disorders and changes the status of clients in family and community. If the person don't get SER in time may be she/he de-habilitate from family and community.

When the PALs get SER opportunity it's process is accommodation, acculturation, assimilation, reintegration and socialization. The socio-economic rehabilitation process starts first from accommodation of PALs with in own family and community. Accommodation is adjusting oneself to the new situation. The person

unknowingly becomes a victim of psychological disorder after knowing the infection of leprosy. In such situation, the PALs needs family support for socio-psychological. The person needs to adjust herself/himself in new physical and social environment. Accommodation is related with adjustment of a person physical or social environment.

Anderson and Parker described (1964) about accommodation as the achievement of adjustment between people that permits harmonious acting together in social situations". When PALs achieved of adjustment in own family and community that creates a good environment for social relationship. In a society the harmonious relationship is most necessary to work together. The entire individual related with each other. There is mutual relationship between the individuals. A person can't survive without society. Accommodation is the natural result of conflict; here conflict is the attitude and beliefs of people about leprosy. The result of beliefs and attitude limits the social participation. PALs always remain a fear of rejection of family and community. The People do not know the causes of leprosy and always back supporting of superstitious and traditional beliefs. Than, they create social restriction with the PALs and their family members.

Similarly, MacIver (1945) refers accommodation particularly to the process in which man attains a sense of harmony with his environment. Until people attain the sense of harmony people can't adjust him/herself in a society or community. The SER starts from accommodation of a client.

The PALs should adjust her/himself in new environment with a fear of knowing the case. During the process of rehabilitation people may loose own culture and gain others. The cause of physical disability is lately treatment of leprosy. Due to poor physical situation of PALs, they have to change or modify their previous

business/job/work. Due to this, for adjustment the PALs acculturate for new job/work with or without modifications. Similarly, when the acculturation process begins the person or groups acquire the culture of the others in which they come to live, by adopting its attitudes and values, its patterns of thinking and behaving, its way of life. People tried to find more about leprosy. The community people get information from different sources such radio, television, awareness and training. Than they change of attitude to adopt them in own society. People acculturate them in society, works, school and development works. Some of them PALs migrate from their original place to other unknown places, where nobody knows him/her. Generally, they migrate near to treatment center and near to city. In such cases the PAL has to adopt new culture and practices.

Gradually the PALs assimilated into the family and community. The assimilation is a social process, it is not limited to particular kinds of groups or person. The PALs includes in own community and family. Here, Bogardus explained about assimilation as the social process whereby attitudes of many persons are united, and thus develop into a united group. Assimilation is a social as well as psychological process. Before individuals or groups once dissimilar become similar: that is become identified in their interests and outlook. At initial stage, …… the process whereby individuals or groups once dissimilar become similar, and identified in their interest and outlook.

In the process of SER next step is re-integration of PALs into owns family or community or in new community. The rejected PALs re-integrate in own society. The aim of SER is to maintain a harmonious and active relationship between the various structural components of society. It not only keeps the society going but also imparts a meaning and purpose to the lives of the individuals so that they felt themselves to be a part of a comprehensible and harmonious social life. The

integration is not only for reform but also for social reconstruction as well. The SER aims to abolish the existing bad social system and attitude and practice of people.

The individual in society is bound together and dependent upon each other in systems of interrelationships that combine to constitute a complete functional structure. PALs reintegrate into family and society harmoniously. Gillin and Gillin (1950) wrote that socialization mean the process by which individual develops into a functioning member of the group according to its standards, conforming to its modes, observing its traditions and adjusting himself to the social situations. The society accepts to PALs in the process of socialization. The process of SER provides dignity, respects and status of the PALs. The process of socialization is gradually changing the individual as responsible member of the particular society.

Social and economic problems are closely related for leprosy-affected person or their family members. The person affected by leprosy is not necessary having a deformity and lost of body parts. Mostly those people having a visible deformity has more social and economic problems but in some cases that have no visible deformity also having social problems.

The “Rehabilitation” is the process of reversing of this phenomenon, which enables one to repossess one’s roles and functions in society. This is the individual’s role in respect to his immediate social milieu, and the processes of de-habilitation as well as rehabilitation involve interactions between the affected individual and the local community. One must also recognize that there are two different dimensions to de-habilitation. The economic dimension refers to the material impoverishment of affected individuals and their families, while the social dimension has to do with marginalisation, isolation and rejection leading to impoverishment of social relations. The two are inter-linked, but not so rigidly as to be totally identified with

each other. Further, the 'social consequences' are far more complex and not all of them are easily amenable to manipulation.

2.1.5 Leprosy and Rehabilitation

There are more than 12 million leprosy-affected persons in the world, who have completed treatment with MDT. Many of them need support for physical and social rehabilitation. Among them there are about 2 million persons with visible disabilities and another 2 million persons with anesthesia of body parts, who risk worsening and developing new disabilities. (Anesthesia is a senseless condition of patches in body parts).

Physical barrier is one of the major problems to access the resources. So that disabled people experience multi-sectoral barriers to participate in paid work. One of the main barriers is because the employer adopts a medical interpretation of disability. They perceive disabled people as inactive, useless and unworthy, hence excluding disabled people from the job market. However, disabled people view disability as a social problem, as listed below:

- Attitudinal barriers that prevent access to employment, retention of work, obtaining appropriate work, career prospects, discriminatory attitude of employers, supervisors and peer groups.
- Institutional barriers that include mandatory requirements of medical fitness certificate for employment lack of inappropriate training and lack of education opportunities.
- Structural barriers include inaccessible work environment and inaccessible transport systems.
- Beyond their physical impairment these barriers perpetuate a disabling society in which disabled people are discriminated against and often excluded from

economic participation. Some positive measures such as job based training, market related training, accessible work environment and support though micro-credit, promote effective participation of disabled people in paid work.

2.1.5.1 Operational Principles of Socio-economic Rehabilitation

Multi drug treatment has ensured those who have impaired, but there is estimated two to three million people with significant disabilities caused by leprosy. Many leprosy-affected people adjust themselves with the effects of leprosy; others need help if they are to resume their previous way of life. The SER must be focused upon the concerns of people affected by leprosy and their families and communities. International Leprosy Elimination Program (2002) identified six common principles of SER.

- The holistic principle: - An awareness of, and responsiveness to, every aspect of life. Concern for the physical, psychological, social and economic well being of people affected by leprosy.
- The participatory principle: - Respect for, and responsiveness to, the voice of the client. People whose self-esteem has been eroded by leprosy, actively involving them in decisions about improving their quality of life. It will help to empowerment the ability of client to make decisions and manage the transactions of everyday life. Client, members of family and the community can be involved in the process, as may local Community based organizations associated with leprosy patients.
- **Sustainability: -** Such activities that bring lasting benefit. The activities should be acceptable to the community and benefit other people. Direct involvement of family and community members and sharing of benefits further increases sustainability. Responsiveness to environmental, seasonal and market factors is also important.

- **Integration: -** Rather than creating new services, should use existing services available.
- **Gender sensitivity: -** Leprosy effect is greater on women than on men in a family or in a community. It should ensure women equally accessing to services and participates actively at all stages.
- **Sensitivity to special needs: -** Such children and older people have special needs. Describes the needs PAL children, identify risk factors and suggests a programme response.

2.1.6 Rehabilitation Work on Leprosy in Nepal

In Nepal, there were few organisations working for the socio-economic rehabilitation for Leprosy clients. The Khokana Leprosarium working in Kathmandu valley started from 1857 by providing them asylum way. Another was started at Malunga in Synagja district in 1939. From 1960s leprosy control activities were started with leprosy surveys. In 1961 first time first sample survey was conducted by the government with the help of WHO in Kathmandu valley and the prevalence rate was found 1 per 100 population (WHO report 1961).

Dapsone was introduced first time in Nepal at 1956 as a scientific treatment of leprosy in these leprosariums. Instead of Dapsone, WHO recommended Multi Drug Therapy. In 1996/97 reduced prevalence rate 5.9 per 10000 populations after introducing of the MDT. More than 47,308 cases were cured upto 1996/97 all over the country and disability grade among new cases remarkably reduced after the MDT extended (Annual report of Department of Health Services 1996/97).

In 1999, National Leprosy Elimination Campaign was conducted in order to bring down the prevalence rate less than 1 case per 10000 populations. The outcomes of

this survey estimated prevalence rate is estimated 8.8 per 10000 populations. WHO reported, Nepal was 6th position in the world.

The World Leprosy Assembly (WLA) 1991 was prompted to call for the "elimination of Leprosy as a public health problem by the year 2000", defining elimination as attaining a level of prevalence below 1 case per 10,000. Leprosy elimination is a globally accepted programme, and its definition and target are used for public health management purposes. Leprosy is a curable disease but it takes time to be cured.

There are few organizations working for the leprosy elimination and rehabilitation work. These organizations focused for treatment and support of the District Public Health Service Office staff.

- **International Nepal Fellowship (INF):** The INF is working in the Western Development Region of Nepal.
- **The Leprosy Mission International (TLMI):** The TLMI working in the Central Development Region of Nepal.
- **The Netherlands Leprosy Relief Association (NLR):** The NLR working in the Eastern Development Region of Nepal.
- **Nepal Leprosy Trust (NLT):** The NLT working in the Kathmandu valley and running income generation activities.
- **The Evangelical Alliance Mission (TEAM):** The TEAM office working in the Far Western Development Region of Nepal.
- Anandaban Leprosy Hospital: This organization working in the Central Development Region of Nepal for treating and socio-economic rehabilitation of leprosy patients.

2.1.6.1 International Nepal Fellowship (INF)

International Nepal Fellowship is a Christian Non-government organisation (NGO). It has been working in Nepal since 1952 AD for improvement of health of Nepali people. INF has an agreement with Ministry of Health and Ministry of Social Welfare Council. Under INF, there are six programs such as INF Kaski programme, INF Banke, INF Dang, INF Surkhet, INF Jumla and INF Mugu Programs. INF Kaski has been working in the Western Development Region (WDR) of Nepal.

INF Kaski Programme (IKP)

IKP is running many activities to facilitate integration of the holistic health care and rehabilitation work of INF across the Western Development Region of Nepal. It includes leprosy, disabilities, rehabilitation and HIV/AIDS works and incorporates community health and development, medical and surgical camps and health services infrastructure development work. Under IKP programmes there are five sections, they are Green Pasture Hospital and Rehabilitation Centre (GPHRC), Outreach Section, Paluwa, Speech and Language therapy (SLT) and Partnership For Rehabilitation.

Green Pasture Hospital and Rehabilitation Centre

This section was established in 1956 AD for treatment of leprosy patients. It has 70 beds, 4 doctors and 45 other staffs. Now these days, 2 beds allocated for HIV+ patient and also admitted for Spinal Cord Injury (SCI) patients. This hospital out patient unit opens every Sunday, Wednesday and Friday. For leprosy related case finding, accommodation, food and treatment is available free of cost. They used to single drug therapy but now days using multi drug therapy, which is very effective.

In hospital, there are nursing unit, occupational therapy unit, physiotherapy unit and orthopedic unit.

Outreach Section

This section has been supporting District Health Office (DHO). The major activities are to provide training to staff of DHO, organise medical camps in different districts with coordination of local partner organisation and DHO. It also carries on leprosy survey in different districts.

Paluwa

This section working for rehabilitation of HIV positive people. The working area is in Pokhara valley and providing training to N/GO DHO staffs about AIDS care, counseling and training. This section advocates on the behalf of HIV positive people. It also runs volunteer counseling and testing (VCT) at nominal cost and involved in network of related organisation.

Speech and Language Therapy

This section supporting to the Gandaki, Western Regional Hospital. The speech and language therapy works jointly with of the Government of Nepal.

Partnership For Rehabilitation (PFR): Partnership For Rehabilitation mobilizes local communities and organizations and supports them as they provide opportunities for the full participation of people with disability. This section is working for the socio-economic rehabilitation of people affected by leprosy, people with disabilities and infected with AIDS. It has been working since 1975. The working area is WDR of Nepal and a district from Central Development Region (Chitwan- only for leprosy affected people). PFR has been working in two ways: Working with individual people or family including community people and Working as partnership with local organization/CBOs/DPOs. It has four units' i.e. Direct client assistance (DCA), Vocational Training for Community Development (VTCD), Community Capacity Building (CCB) and Management, Administration and Support unit (MA&S). A brief explanation of each unit is as follows:

PFR, Direct Client Assistance Unit (DCA): PFR directly works with individual client or family and involving community people for socio-economic rehabilitation and raise self-esteem of targeted clients. The main objectives of DCA unit are:

- Rehabilitate the target family in society to actively accept and participation in all community activities.
- Economically self sustain and independent by running different income generating activities.
- Advocate on the behalf of PALs/ PWDs/ PLWHAs people for their right and dignity.

PFR, Community Capacity Building Unit (CCB): This unit supports to capacity builds up of the local partner organisation through providing training. PFR has fifteen local partner organisations. Out of fifteen some are getting full support i.e. staff cost and activities cost, some are only for technical support and some LPOs

either staff cost or activities cost supported by PFR. The main aim is to builds and sustains capacity of local partner organization for technically and financially.

PFR, Vocational Training for Community Development Unit (VTCD): VTCD has two sub units. The Rural Development farm (RDF) and Vocational Resource and Training Centre (VRTC). The main aim of these two sub units are to be self-sustain financially and managerial, to provide training to the clients or theirs family members. The training are agricultural based and non-agricultural based i.e. weaving, driving, tailoring, card making, painting, buffalo keeping, goat keeping, pig keeping etc. The duration of training varies from 3 days to 18 months. Before approval of training need to carry on vocational assessment of clients. VTCD provides piecework and daily wages work in farm and workshop of PFR.

PFR, Management, Administrative and Support Unit: The aim of unit is to support other units of PFR in regards of administrative and managerial support. This unit planning, monitoring, evaluation, reporting to meet overall goal of PFR.

2.1.6.2 Provision of Services by the Government of Nepal

The Government of Nepal has no specific activities on socio-economic rehabilitation programme for the leprosy-affected peoples. The Government of Nepal focused only to reduce prevalence rate of leprosy is less than one per 10,000 populations at the end of 2005 AD. Supporting for multi drug therapy (MDT) through health post/sub health post/clinics. The medicines and treatment of leprosy is available at free of cost in all hospitals, clinics and health post of the Government in Nepal.

Nepal Leprosy Relief Association (NELRA)

This organization was established in 1857 A.D. in Kathmandu especially focusing the leprosy patients. NELRA is a non-government organization working jointly with the Government of Nepal. The NELRA has been running vocational training and social welfare activities. The PALs are not much familiar with this programme. Some old PALs getting living support and some for vocational training (that is metal craft and woodcraft training). Some old aged PALs having living support at their centers.

The prevalence rate of WDR is 1.82 per 10000 populations. Similarly, the prevalence rate of Nepal is 1.65 percent. It shows the new case detection is higher than the target of elimination rate. Most of the studies referred for socio-economic rehabilitation are major activities for leprosy-affected people. The medical rehabilitation alone cannot eliminate the social stigma. Economic rehabilitation is only possible after eliminates of social stigma. In the process of SER, accommodation, acculturation, assimilation, re-integration and socialization are the major steps of SER. If the client is not successful to integrate into own society than he/she de-habilitates from own family and community. Grade 2 disability has the high social and economic problem compare to Grade 0. Similarly, female was higher vulnerable situation than male in family as well as in community.

In conclusion, there are very few organizations working for the socio-economic rehabilitation. Most of them are carrying out change attitude of the client, family and community about leprosy and it's causes. The Researcher concerned to identify the change of the Knowledge, attitude and practices (KAP) in client, family and community. Change is a gradual and continues process; it takes time to change attitude, knowledge and practices. Social problem is causes of dis-integration of the

society. It is the way of de-habilitation of the client from own community. Economic problem is related with social problem. No participation and less opportunity are the causes of less income and dis-integration into the society.

Socio-economic rehabilitation plays a major role to reduce social stigma. A few organizations are implementing SER in the Western Development Region of Nepal. This study is very important to know the impact of SER. Social stigma is one of major causes to check the economic growth of PALs. De-habilitation is ways make the person disintegrate from a society. Disability with leprosy and social stigma is close to encouraging a person for begging. They don’t get opportunity to work and participation, loss of self-dignity of PALs.

CHAPTER-III

RESEARCH METHOD

3.1 Research Design

This study is based upon sociological and economical aspects of leprosy-affected people. Socio-economic impact study is related with leprosy-affected people and their community. This study explains the change of client situation in regards of social and economic change of leprosy clients. The research design of this study is exploratory and descriptive. The exploratory design is applied for the exploration of social and economic changes of leprosy clients. The analytical design analyzes impact of change in different variables. The different variables are closely related for effect of social and economic changes. Similarly, description of the general information regarding social and economic changes describes the impact of rehabilitation works.

The interview has been taken in community with community key informants and leprosy clients. The respondents are categorized into two categories. They are a Leprosy clients, who has got support regarding socio-economic rehabilitation from Partnership For Rehabilitation, International Nepal Fellowship (PFR, INF) and other respondents are key informants of related client's area. (Such as Female Community Health Volunteer (FCHV), Member of mother group, Teacher, Village Development Committee members etc).

The researcher used main tools are observation, interview and questionnaire with individual people. The questionnaire is structured with different options. An interview has been carried out with key informants using open question-answer. At

the time interview, the enumerator directly observed the changes in economic situation and social situation of clients. The data collector fined real picture of individual client, a community and district. The collected information is quantitative rather than qualitative. So, information collected within a structured questionnaire for leprosy client and open question for the key informants. In addition, this research carried out in the Western Development Region of Nepal, that is who has rehabilitated by PFR, INF.

3.2 Area of Study

Nepal is divided into five-development region, fourteen zone and 75 districts. PFR has been working in the Western Region of Nepal and one district of Central Development Region (Chitwan). Under the Western Development Region, there are sixteen districts. Also the Western Development Region is divided into three ecological zones. They are Southern part is Terai, middle part is Hill and northern part is Himalayan Mountain.

Figure: 3.1

Map of Western Development Region

Table: 3.1

Abbreviation of Name of District

Mn	Manang	Pr	Parbat	Gr	Gorkha	Ar	Arghakhachi
Ms	Mustang	Ks	Kaski	Sy	Syangja	Kp	Kapilbastu
My	Myagdi	Lm	Lamjung	Pl	Palpa	Rp	Rupandehi
Bg	Baglung	Tn	Tanahun	Go	Gorkha	Np	Nawalparashi
Ch	Chitwan						

Four districts of Western region are Gulmi, Myagdi, Manang and Mustang were excluded from this study because of no assistance had given for leprosy patients

from PFR in 3 districts during that period and in Gulmi the clients were migrated to India.

3.3 Selection of Respondents

The researcher collected the entire annual client list that got support housing and income generation in 2000, 2001, 2002, 2003 and 2004 from PFR Section. The target people of PFR are poor and marginalized people affected by leprosy, disabled people and people affected by HIV positive. PFR provides different type of support such as Income generation, Vocational training with business, education, housing, living support for old or highly physical disable, referral and medical support.

Primary respondents were the sampled clients of PFR. These people were economically very poor and couldn't afford or construct their house. Second type of respondent was the person who is staying near to leprosy client such as teacher, Female Community Health Volunteer, Village Development Committee member and Member of Mother Group. So, the second type of respondents could be non-leprosy people.

For this study, the target population is people affected by leprosy and got support for income generation and housing. Researcher made a list of receiver as district-wise. And put them serial number such as 1,2 3 … Every new district starts from 1, 2 … There were two types of respondents in this study.

Table: 3.2

Respondents Selected District Wise

District	Total respondents	Percent (%)	Total selected
Gorkha	8	60	5

Lamjung	5	60	3
Baglung	7	70	5
Myagdi	0	0	0
Manang	0	0	0
Mustang	0	0	0
Tanahun	10	50	5
Kaski	42	40	16
Parbat	10	50	5
Synagja	11	50	6
Palpa	2	100	2
Gulmi	0	100	0
Arghakhachi	3	100	3
Chitwan	8	50	5
Nawalparashi	25	40	10
Rupandehi	20	40	8
Kapilbastu	4	100	4
Total	155	55%	77

There were 155 leprosy clients getting support for income generation and housing. The researcher sampled 55 percent of leprosy client out of from 155 respondents. The selected number was 77 clients out of 155 clients. (See name list of leprosy client who has got support for income generation and housing). Leprosy affected people of Kaski, Nawalparashi and Rupandehi districts are highest population for socio-economic rehabilitation. Because, the people migrated from village of Kaski district and other district of WDR as well as other development region for work in Pokhara and for treatment in Green Pasture Hospital, Pokhara. They gradually settled down in surrounding of Pokhara valley. There were no clients rehabilitated by PFR in four districts such as Manang, Mustang, Myagdi and Gulmi during that period. Out of 17 districts, two districts hadn’t female respondents.

3.4 Sources of Data

The secondary data of clients were collected from the list of PFR. PFR is only one Organisation, which is working for socio-economic rehabilitation since 1975 AD.

The secondary data gives the researcher information as follows:

- Name, address, family members
- Types of support and how much money for that particular items.
- When it was supported

The primary data were collected from the different district of the WDR of Nepal and one district Chitwan from the CDR. Because many leprosy clients were settled in this district since 1975. The organization is supporting to PALs in these areas for socio-economic rehabilitation.

3.5 Sampling Procedure

The researcher made a list of clients who got support from PFR during 2000-2004. Researcher sampled by the lottery method. The sampling number was according to district client density. It was sampled 77 clients out of 155 clients. Random sampling method used to collect the list of respondent. Under random method, lottery method was used to select the name of the respondents. There were equal chance to all respondents be a respondent. The respondents were sampled as district wise of the clients. There were no biased among the respondent for the selection procedure. The researcher made a name list of all respondents; selected clients were based on the geographical region. Those non-leprosy respondents were the members of the same community of the respondents. Out of 77 clients, only 59 respondents have been filled up questionnaire.

3.6 Field Work and Data Collection

The researcher took approval from research supervisor and research committee of the, Department of Sociology/Anthropology. The researcher discussed with Supervisor about the questionnaire and it was little modified. Interview was major tool of this study; it was taken with individual people. Similarly, observation was another tool to know the real situation of clients.

The researcher selected three persons to fill-up questionnaire. Researcher gave one-day orientation training about the questionnaire and the questionnaire was pre-tested. It also helped the researcher to know the area of developing the enumerator to fill up the questionnaire. They filled up ten questionnaires around the Pokhara valley. Pre-tested questionnaire helped the researcher to modify the question. First, the enumerator sent nearest client of PFR to collect the data. It was thought that if they get problem to get right answer than they will need more help but it was not happened.

The address, name list of respondents given to the enumerators. Also, the researcher visited with them in certain areas. The questions were closed type to get the answer for leprosy-affected clients. For non-leprosy respondents were used open questions. 59 respondents has been attended the interview.

3.7 Methods of Data Collection

The rehabilitated clients were not in a single cluster or a single village / village development committee. The targeted individuals were poor and marginalised people of the WDR of Nepal. They were scattered in different district of remote areas.

The primary information was collected by questionnaire with direct interview with leprosy-affected people in their home. During home visit, the researcher observed

the current situation of support. There were many variables used for socio-economic study and they were related with each other. Especially variables were related with social and economic situation. Here, the researcher's focused on impact of Socio-economic rehabilitation of leprosy-affected people in the Western Development Region of Nepal.

Also case study of income generation was included to qualify the quantitative data. Key informant interview: Key informant interviews were conducted to obtain information from closely related neighbors, teachers, and political leaders of PALs. It was conducted to know the attitude of the people about leprosy and what practices they use.

3.8 Data Analysis

All the collected data were analyzed in the Epi-info statistical processing programme. Collected information from the key informants was analyzed qualitatively. Data are presented in terms of frequency, percentage, and distribution in graphs and tables.

The following procedures were used for quality control, categorization and tests in the process of data analysis.

- All the variables coded suing the corresponding question numbers in the questionnaire form.
- The questions were selected and grouped by their relation to a hypothesis and analysis was done.
- For categorical analysis, such as cross-tabulation.
- Simple statistical analysis such as cross tabulation, frequencies. The result is presented in tabular and graphical forms.

3.9 Missing Respondents

Eighteen clients could not meet at the time of interview. Few of them migrated to other places; few of them went to work in other parts of Nepal and India. Few of them had died. The researcher attempted to trace and interview all the sample clients, but the total sampled clients could not be traced or were not available during the interview time.

3.10 Conceptual Framework

Leprosy is highly stigmatizing disease in the world. When people knew about the infection of leprosy, people will try to hide it from others due to fear of social rejection. Sometime people don't know the reason of leprosy and goes to treatment first in the traditional healers. Due to wrong diagnosis, the health situation becomes worse. If they don't get right treatment and not adopt required precautions than it causes physical disability.

The visible disability is the main cause to limit person to participate social and economic activities. The situation of limitation leads to restrict participation, family & community relationship, marriage problems and employment problems. It causes the psychosocial problems.

The situation of limitation is causes of poverty. The poverty leads to begging if don't get proper socio-economic rehabilitation. Than person de-habilitate from own family, own community and own society. The leprosy affected person or their family members needs of socio-economic rehabilitation. The process of rehabilitation is accommodation, acculturation, assimilation, socialization, and reintegration.

Accommodation is related with adjustment of a person physical or social environment. A person can't survive without society. Accommodation is the natural result of conflict; here the PALs have conflict of social thought and limitation of participation. The PALs always remain in fear of accommodation. People do not know the causes of leprosy, and it behaves social restriction unconsciously.

Anderson and Parker described "Accommodation is the achievement of adjustment between people that permits harmonious acting together in social situations". The socio-economic rehabilitation is the first step to accommodate the PALs in own family and community.

Similarly, MacIver described, "The term accommodation refers particularly to the process in which man attains a sense of harmony with his environment". Until man attains the sense of harmony people can't adjust him/herself. The accommodation is the ground of SER.

The PALs should adjust her/himself in new environment. During the process of rehabilitation people may loose own culture and gain others. The acculturation process helps to adjust the person in new situation or condition.

Similarly, when the acculturation process begins the person or groups acquire the culture of the others in which they come to live, by adopting its attitudes and values, its patterns of thinking and behaving, its way of life. Gradually the PALs assimilated into the family and community. The assimilation is a social process, it is not limited to particular kinds of groups or person. The PALs includes in own community and family. Here, Bogardus, "Assimilation is the social process whereby attitudes of many persons are united, and thus develop into a united group". Assimilation is a social and psychological process. Before individuals or

groups once dissimilar become similar: that is become identified in their interests and outlook.

The next step is re-integration of PAL's into owns family or community. The aim of SER is to maintain a harmonious and active relationship between the various structural components of society. It not only keeps the society going but also imparts a meaning and purpose to the lives of the individuals so that they fell themselves to be a part of a comprehensible and harmonious social life. The integration is not only a reform but also a social reconstruction. The SER helps abolish the existing social system and attitude and practice of people.

The PALs reintegrate into family and society harmoniously. Gillin and Gillin write, " Socialization mean the process by which individual develops into a functioning member of the group according to its standards, conforming to its modes, observing its traditions and adjusting himself to the social situations". The society accepts to PALs in the process socialization.

Than the process of SER provides dignity, respects and status of the PALs. The process of socialization is gradually changing the individual as responsible member of the particular society. Social and economic problems are closely related for leprosy-affected person or their family members. The person affected by leprosy is not necessary having a deformity and loss of body parts. Mostly those people having a visible deformity has more social and economic problems but in some cases that who have no visible deformity also have social problems.

The "Rehabilitation" is the process of reversing of this phenomenon, which enables one to repossess one's roles and functions in society. This is the individual's role in respect to his immediate social milieu, and the processes of de-habilitation as well

as rehabilitation involve interactions between the affected individual and the local community. One must also recognize that there are two different dimensions to de-habilitation. The economic dimension refers to the material impoverishment of affected individuals and their families, while the social dimension has to do with marginalisation, isolation and rejection leading to impoverishment of social relations. The two are inter-linked, but not so rigidly as to be totally identified with each other. Further, the ‘social consequences’ are far more complex and not all of them are easily amenable to manipulation.

Figure 3.2: Conceptual Framework of the Socio-economic Rehabilitation

CHAPTER- IV

OVERVIEW OF THE STUDY AREA

4.1 Physical Setting and Demographic Profile of Respondents

Nepal is a developing country. It is a country of Southern Asia region. It is a landlocked country situated between the Republic of China and India. The northern part of study area is connected with China, southern parts with India, eastern with Pursa, Makwanpur, Dhading and Dolkha district. In addition, west part of study area is connected with Dang, Pyuthan, Rolpa and Rukkum districts. The northern part of country border is mostly covered by snow. There is open border between India and Nepal.

This study was carried out in the Western Development Region of Nepal and one district of the Central Development Region of Nepal. The WDR lies between the CDR and Mid-WDR of Nepal. The eastern part is connected with the CDR and western part with mid-WDR. There are three zones: Gandaki, Dhaulagiri and Lumbini. In the WDR of Nepal have 901 Development Committee, 13 Municipality and one Sub-metropolitan. The WDR has occupied sixteen districts i.e. Kapilbastu, Rupandehi, Nawalparashi, Gulmi, Arghakhachi, Palpa, Syngja, Kaski, Tanahun, Lamjung, Gorkha, Parbat, Baglung, Myagdi, Manang and Mustang. One district of the CDR has been included in this study because the PFR programme has been rehabilitating the leprosy-affected clients since a long time. Thus, the Chitwan district is included in this study.

4.1.1 Population

The total members supported by PFR are male 118 and female 37. The ratio of sampled population 2.57:1 between male and female respectively. There are 77 households in this study. The populations selected for interview are Chaudhary 3, Yadav 2, Brahmin 12, Chetri 9, Gurung 5, Magar 15, Baram 1, Kumal 2, Pariyar 8, Sunar 4, Bishwakarma 13, Chammar 1, Dhawal 1 and Mahato 1

Out of 77 households, only 59 households attended for interview. The total family members of sampled population are 295. Out of 295, male populations are 168 and female populations 127.

4.2 Demographic Characteristics of Respondents

Altogether 77 individuals were sampled for an interview from 14 districts. The sampling was not on the basis of high prevalence district. It was based on PFR support during certain period of time for income generation and housing support. Kaski district was the highest number of leprosy patient who have got socio-economic rehabilitation. The reason behind being more number is PALs migrated from their original place to Pokhara for treatment and work. And in cases, they left own community due to social stigma and economic problem. In Pokhara the social stigma was lower than the other places. Mostly PALs came Pokhara to get treatment easily. Other reason being highest population of leprosy in Kaski was included the clients of NELRA rehabilitated in 19 households near to Lekhnath municipality. Also, PFR supported in this asylum for pipeline for drinking water system.

The total family members were 101, who were jointly associated with respondents. The total family member in the study sample was 101. They were 49 male members and 52 female members. The table 4.6 shows the total respondents were 59, female

17 and male 42. The sex ratio of male and female is 2.47:1 respectively. The percentage is 28.8% females were affected by leprosy and 71.2% male have received support from PFR. The infected number of male was higher than female. It shows that male were more in contact with various community people than female. The female has less opportunity to contact with other people. The male moves for work in different places of neighboring country. Due to that male was higher than female.

Table: 4.1

Distribution of Sampled Respondents by Districts and Sex

Name of district	Male	Female	Total
Gorkha (Gr)	5	0	5
Baglung (Bg)	4	0	4
Tanahun (Tn)	3	2	5
Parbat (Pr)	2	3	5
Lamjung (Lm)	2	1	3
Kaski (Ks)	12	5	17
Syangja (Sy)	4	1	5
Arghakhachi (Ar)	2	1	3
Palpa (Pl)	1	1	2
Chitwan (Ch)	2	3	5
Nawalparashi(Np)	8	2	10
Rupandehi (Rp)	6	2	8
Kapilbastu (Kp)	2	2	4
Myagdi (My)	0	0	0
Manang (Ma)	0	0	0
Mustang (Mu)	0	0	0
Gulmi (Gl)	1	0	1
Grand total	**54**	**23**	**77**

4.2.1 Age Composition

Leprosy is not caused of genetic. It can infect all ages of people. The age of respondents in this study was included from 5 years to above 61 years. In the table 4.7, among 59 respondents, 4 respondents were less than 20 years, 11 under age between 21-40 years, 25 under age between 41-60 years and 19 were above 61 years old. This data shows that all age groups were affected by leprosy. Leprosy can infect any age group of people and mostly during productive age between 21 to 40 years. When they admitted in hospital, they have to take medicine 6 months to 12 months regularly. In such situation, they have to take rest without hard works. In a poor family, it is difficult to manage it. In such situation they need support for income generation.

Table: 4.2

Distribution of Age Group of Respondents

Age group	Frequency	Percentage (%)
Less than 20 years	4	6.8
21-40 years	11	18.6
41-60 years	25	42.4
Above 61	19	32.2

4.2.2 Religious Composition

Nepal is a country of multi ethnic groups. They believe on different religions. 83% respondents believe on Hinduism, which is the main religion of Nepal. Similarly, 16% respondents out of 55 were Christian and only one percent Buddhist and none of them Muslim. Sixteen Hindu and one Christian were female respondents in this study. Similarly male respondents were thirty-three Hindu, eight Christian and one Buddhist. None of the Muslim respondents had support from PFR. In Hindu,

Swasthani Barata Katha mentioned, “the bad wishes of God were the cause of leprosy”. Knowledge and attitude of people were affected by religion.

4.2.3 Educational Status

Out of 59 respondents, High school 9, Primary school 7, Literate (read and sign simple words) 16 and completely illiterate 27. None of them had Campus level education and vocational training. 32 respondents were literate, out of 32 respondents 27 male and 5 female.

4.2.4 Citizenship

All Nepalese people should have own Nepali citizenship. But few of the respondents have not Nepali citizenship because they were migrated into other parts of country due to social problem. Some of them migrated for treatment and seeking work. The 10 respondents have no citizenship out of 67.

4.2.5 Marriage and Divorce

Everyone would like to marry with a good or beauty girl or boy. In some cases due to leprosy create problem of marriage of PALs or family members. Leprosy can cause problem before and after knowing or to get good partner. For both sexes were having problems of divorce. Sometime, there is problem for family in family members to get son-in-law or daughter-in-law. Out of 59, married clients are 51 and 8 are unmarried. Two out of 8 respondents are unmarried due to the cause of disease.

When people knew about the infection of leprosy than seen the symptoms of depression. Between husband and wife they were not sharing the infection of leprosy. PALs hide herself/himself about the disease because it was the causes of divorced. There is possibility of breakdown the relationship between husband and wife. The Researcher was found 7 respondents out of 59 has divorced due to leprosy. Out of 7 divorced cases, 4 were females and 3 males cases found in this study. The literature has shown divorced cases higher in female than male. The situation of divorced was high in rural area compare to urban. Rural people are not familiar the cause of leprosy. In Nepal, the rate of illiteracy is higher in female compare to male. Due to illiteracy, people believe on fate, superstition and bad "karma" in past life. It is the cause of lacking knowledge, traditional believes and thinking about leprosy.

4.3 Health Services

The table 4.3 shows, 4099 health services centers providing services in the WDR. In 2003/04, the health centers treated total patients 14533813. A VDC has one health post or sub health post. Generally each district has one hospital. Also government runs primary health care centre or health clinic in each district. Each zone has zonal hospital and regional hospital.

Table: 4.3

Available Health Facilities in Nepal

Health institutions		
Report received- 900	Total institution number	Patient number (old + new)
Government's hospital	84	30,49,011
PHCC/HC	188	16,60,267
Health post	698	31,74,895
Sub health post	3,129	66,49,640
Total	**4,099**	**1,45,33,813**

The figure 4.1 shows total infectious disease of new cases was treated 58,99,265 in 2003/04. There were 24% of total treated patients visited in health centers for skin diseases (1488848) such as mange, ringworm, soriasis, leprosy etc. Leprosy is also included under a skin disease of human being.

Figure: 4.1

Treated of Different Types of Health Diseases

Similarly, the acute respiratory infection was treated 18 % of the total patients (1069660). ARI mostly infects the children and old people. Some examples of ARI are Pneumonia, cough, asthma and sneezing. The 8% patients were treated for ear infection (445102), 7% for Sore eye & complaints (423802) and 6% of chronic bronchitis (347144). There was 10% of each treated such as Pyrexia of unknown disease (585795) and Gastritis (583098). There were 5% patients treated for diseases Falls, injuries, fractures (269745), Abdominal pain (277399), Toothache & others com plains (275995). The least patients were treated 2% for urinary track infection (132677).

4.3.1 Health Problems of Leprosy Affected People

Good health is everything in human life. Without healthy life no one can do good thing and contribution to the nation. Health is wealth. What kind of other health problems could be occurred? The table 4.4 shows the 59 respondents, who were identified a list of 19 different health problems. One of the major problems is itching body. They were as follows:

Table: 4.4

Health Problems of PALs

Name of health problems	Frequency	Name of health problems	Frequency
Allergy	8	Respiratory disease	2
Paralysis	8	Blood pressure high	2
Tuberculosis	5	Epilepsy	2
Pain in legs/hands	5	Cancer	1
Jaundice	5	Anemia	1
Headache	4	Sun itching	1
Body vibration	4	Ulcer	1

Body swelling	4	Diabetes	1
Dubi (white spot)	2	Cough	1
Fever	2		

4.4 Disability Profile of Respondents

Two types of bacteria are the cause of Leprosy. Both types of bacteria i.e. pausi-bacillary and multi-bacillary infected the respondents. WHO graded disability into three levels i.e. 0, 1, 2. This grading shows the disability level of Eye, Hand and Feet level. The grading system is according to functional limitation of the human body.

4.4.1 Disability Grade of Eyes

Out of 59 respondents, two have grade 2 disability in eyes. The two respondents have lost one eye. 15 respondents have Grade 1 disability of low vision. 42 respondents have normal eyes. Leprosy disease affects on eyes i.e. Due to leprosy, eyelid become always open and can't blinking and rooted out eyebrow. Both lids of eyes haven't close at the time of sleeping. Due to this reasons, easily enter unwanted dust and insects inside the eyes to injure. The eyelid-blinking problem easily damages the eyeballs; continue tearing, drying and loss of vision.

4.4.2 Disability Grade of Hands

Similarly, the disabilities of hands 13 respondents were Grade 2 disability. They have lost their fingers and hand palm due to leprosy. Mostly they were poor and labour work for the source of earning. Hard and unrest work with anesthesia hands cause of disability. They were not taken treatment in time and also tried to hide from others. Meanwhile, the 11 respondents have Grade 1 disability i.e. swelling of vein, anesthesia and ulcer. Some of them the structure of hands has deformed. 35 respondents had normal hands.

4.4.3 Disability Grade of Feet

Out of 59 respondents, 24 respondents were Grade 2 disability, which lost toes and foot. They should wear special shoes to prevent to be ulcer. 9 respondents were Grade 1 disability, their feet has anesthesia and swelling of vein. 26 respondents were normal in condition.

Leprosy affects mainly in peripheral nerves system and super facial part of the skin. Initially it looks a simple patch on the skin and if people would not take treatment in time it creates serious problems. Leprosy is a highly stigmatize disease in Grade 2 and 1 compare to Grade zero disability. People hide it from others because of stigmatization without taking any medical treatment. Than leprosy slowly damages many parts of body.

4.5 Size of Household Respondents

The PALs live with their family members in own community. The respondents were selected from 35 VDC and Municipality of 6 districts. The total family members of 59 respondents were 234. Out of 234 were 126 female and 108 male. The size varied from zero to nine members in a family. The sampled household size was average 4.33. The socio-economic rehabilitation was a rehabilitation programme to include client, family members and community people.

Table: 4.5

Average Household Size

No. of members in the households	Total household	Percentage (%)
0	5	8.47
1-3	22	37.29
4-6	23	38.98
7 and above	9	15.26

The 4.8 table shows that total sampled household was 59, 8.47 percent has no family members, 37.29 percent belong to the family size of 1-3 persons only, 38.98 percent belong to the family size of 4-6 and 15.26 percent belong to the family size of 7 and above.

4.6 Types of House and Settlement

Types of house vary from concrete with cemented house (stone or brick), stone and mud wall. Thatch roof or tin roof or stone roof, some house used of bamboo or *narkat* (it is a plant, size of stem is 10 feet tall and hollow stem and no branch) wall with thatch roof. The house rubbed with mix of dung and mud. White colour use to paint the houses and also red soil. Generally, houses are made up of cement with blocks and tin roof, stone with cement, brick with cement or stone with mud. Most of the communities do not get of thatch (khar) or it might be very expensive compare to tin sheet and also it’s durability is less.

The 4.9 table shows the 42 clients having tin roof with stone/brick wall. Thirteen client's house roofed by thatch. None of them has plastic covered house. The four respondents have no land and staying in rented home.

Table: 4.6

Types of House

Types of house	Frequency	Percentage (%)
Tin, stone, brick, cement/clay	42	23.7
Thatch roof	13	22
Covered with plastic	0	0
No house	4	6.8

4.6.1 PFR Support for Housing

PFR has been supported to construct house of client. PFR provides materials and wages to clients. PFR supported to construct new and/or repair house. PFR recommended standard size of PFR is 22'*10' for two rooms + 22'*3' corridor (Branda). In some cases, to repair house such as roof repair, toilet construction and supporting for drinking water. PFR supported 7 respondents to make new house. The budget ranges from NRs. 45,000-1,50,000. 19 clients have support to repair their house. The house repair includes supported tin sheet or toilet materials or water pipe line or kitchen room. The amount of budget to repair varies from NRs. 2000-22000. The total amount spent for 26 respondents were NRs. 6,07,816. Some of them were completely new settlement in new place. Housing support is the major activities of PFR. Out of 26, 6 houses were supported with other income generation activities such as 1 house with pig, 1 house with buffalo and 4 houses with goats.

Photo: 4.1

A House Supported by PFR: Nawalparashi

Table: 4.7

List of Respondents Supported for House Construction

Name of clients	Budget	District	Remarks
Laxmi Bhusal	8500	Parbat	House
Ganesh Gauli	57000	Lamjung	House + Goat
Surya Kumari Bisural	11000	Lamjung	House
Bishnu Maya B.K.	44500	Tanahun	House + Goat
Kausila Sunar	2000	Kaski	House
Mohan Thapa	11250	Kaski	House
Budhi Bahadur Pariyar	5750	Kaski	Pipeline
Chandra Bahadur Gurung	5750	Kaski	Pipeline
Chandra Bahadur Chetri	5750	Kaski	Pipeline
Jasmati Thapa	5750	Kaski	Pipeline
Dal Bahadur Pariyar	5750	Kaski	Pipeline
Khar Singh Gurung	5750	Kaski	Pipeline
Utisuwa Damini	3000	Kaski	House
Iccha Bahadur B.K.	6000	Kaski	House
Khadaka Bahadur Gaha	12200	Syangja	House
Dev Bahadur Magar	5000	Syangja	House
Devilal Neupane	19000	Palpa	House
Krishna+ Mansari Kumal	103600	Chitwan	House + Pig
Prasad Gurung	29800	Nawalparashi	House
Bhakat Bahadur B.K.	14500	Nawalparashi	House + Goat
Shrimaya Saru	45000	Nawalparashi	House
Jhinku Harijan	32000	Nawalparashi	House
Narayan Prasad Mahato	22000	Nawalparashi	House
Jange Pariyar	60966	Nawalparashi	House + Goat
Govinda Ahir	68000	Nawalparashi	House + Buffalo
Surya Kumari Chaudhary	18000	Rupandehi	House

The respondents for housing were one house in each district constructed during that time in Parbat, Tanahun, Palpa, Chitwan and Rupandehi. Similarly, Lamjung and Syangja have two clients. The figure 4.4 shows the 7 clients of Nawalparashi and 10 of Kaski have received housing support during that period. There were many housing clients supported by PFR but sampled only 26 for this study. During that period, the PALs of nine districts received for housing support. In Kaski district, numbers of clients were highest than other districts but the amount of budget is less.

CHAPTER- V

SOCIAL REHABILITATION OF LEPROSY AFFECTED PEOPLE

Social rehabilitation is integration of the clients in own society with own family. Various type of training, awareness activities helped to reduce social stigma. PALs are worry about isolation from family and community. Socio-psychological treatment is more expensive than medical treatment. They were segregated from own community but family support was the crucial role to be depressed and isolate from the community. Also family members weren't like to make relationship with PALs because of rejection from own society. Leprosy limits the client and his/her family members for the participation and creates the problem of economy.

5.1 Issues of Known and Unknown Cases

Social stigma of leprosy is highly rooted in the society. It is fear of transmission, fear of breakdown relationship and traditional beliefs; people hide it from others as well as within family members. The PALs don’t like to disclose as known of leprosy-affected client. Mainly the employer does not want to use them for work. Of course, in some cases it was big issues in community it is transmittable and should isolate from the community and public places. Physical disability of grade 2 disabled easily diagnosed by others but Grade 1 and 0 is difficult to distinguish. Social problem is higher compare to grade 2 and 1. So that social problem is high in Grade 2 disabled clients. Few of the respondents were unknown because of social problem for/in family and community.

Among 59 respondents, 51 respondents were known and 8 unknown by community and family about infection of leprosy because it may cause problem of social stigma. They didn’t disclose about the infection of leprosy. The unknown people

were no disable and deformed. Similarly, 54 respondents known and 5 respondents were unknown by the Co-worker or employer about the infection of leprosy.

5.2 Inclusion with Family Members

Lack of knowledge about the leprosy is cause of social rejection, the family members didn't live together with PALs. Most of the PALs were isolated from their family and community. 53 respondents lived with own family members, 3 respondents separately, 2 with neighbours/relatives and one single person. 45 respondents said the family members were asked before making any new decisions, 9 respondents sometimes, 1 respondents never asked and 4 respondents were not at a decision making level. One of the sign acceptances by family member is the utensils (eating plates od PALs) keeping together with other family member of house. Almost all respondents agreed that the utensils of their keep same place where others keep.

5.3 Attitude of Community about Leprosy

The levels of knowledge of community people about leprosy are taken from the respondents' views. The table 5.1 shows 1 respondents said it was transmittable disease so far such person should isolate from the community, 16 respondents said it was the cause of past life of bad activities or result of sinful activities. 8 respondents answered that such disease can infect to anyone so that we should include him or her into mainstream of development and not to isolate them. 19 respondents said, it is a curable disease if the client takes medicine in time. 15 respondents couldn't answer what other people think about leprosy.

Figure: 5.1

Knowledge of Community about Leprosy

5.4 Knowledge of Respondents about Other People and Social Problem

Due to illiteracy some of the PALs don't know the causes of leprosy. The 5.2 table shows out of 59 respondents, 11 respondents could not answer the causes of leprosy. Some of the PALs agreed that infection of leprosy is the cause of result of past life. 3 respondents agreed it is result of past life and they did bad activities that harm to others. Similarly, 4 respondents consider it was the bad wishes of God as punishment to them to be leprosy. These respondents lost their fingers of feet and hands. 41 respondents agreed it was like other disease and it was not the causes of bad work of past life and bad wishes of the God.

Table: 5.1

Knowledge of Respondents about Leprosy

Reason being leprosy	**Frequency**	**Percentage (%)**
Don't know	11	19
Result of previous life	3	5
God bad wishes	4	7
Similar to other diseases	41	69

When analyzing the depth of acceptance problem in family, neighbor and community, the figure 5.2 shows that among 59 respondents, 58 respondents had no problem, 1 respondent had little problem in family. None of them was rejected from family members.

Similarly, 31 respondents said they had no problem from neighbor. They have good relationship with their neighbor and sharing everything each other. About 27 respondents said they had sometime problems with neighbor and always fear of

rejection or fear of bad words. Among them, only 1 respondent said that he/she faced many problems but none of them was rejected from neighbors.

Figure: 5.2

Behavioral Change with PALs

5.5 Feelings of Inclusion

There are some behavioral practices with leprosy affected client and non-leprosy person. When staying together in family or in community makes feeling of closeness, also share of food items given by leprosy-affected person to non-leprosy. Similarly, respect is also a part of acceptance. Everyone has born with rights of freedom, dignity and equality. Such behavior and practices make feeling of acceptance. When people feel of acceptance than share feeling to others. The researcher asked 59 respondents about the acceptance of society, 50 respondents answered “Yes” and 9 “No” about feeling of acceptance. Similarly, 52 respondents said that the co-worker accepted at their work, 7 said “No”. Out of 59 respondents, shopkeeper to buy or sales of goods accepted 51, and 7 said not accepted. Out of 45 male respondents, 39 were going to barber shop for hair cutting and 6 said “No”. Similarly, 56 respondents said that they were going to take water in public tap. Rests 3 are not going due to lower caste. In addition, 54 said they were going to temple and 5 respondents were not going to temple due to leprosy. 55 respondents said the religious leaders accepted the alms and 4 respondents said not accepted the given alms. 53 respondents were using public transport and only 6 were not using the public transport to travel in different places.

Figure: 5.3

Feeling of Acceptance of PALs

Around 42 respondents felt of respect by community people. 10 respondents said community people respected them sometimes. Only 3 of respondents said nobody respected to them. 4 respondents didn't know about the feeling of respect by others.

Every society has many social activities and social function. The human beings are social living being. Without society, no one can survive alone. Community is more than two people live together and having interrelationship. There is interrelationship to give and take as well as support to each other. The figure 5.4 shows that out of 59 respondents, only 6 respondents agreed that they were staying in leprosy colony and rest in own community. 47 involved in social activities and 50 living with other community people.

55 respondents said freely moving in own community and no obstacles moving with children. 54 respondents freely move with children to stay and visit in community. 56 respondents said acceptance of co-workers at work place and family members by community.

Figure: 5.4

PALs Acceptance in Public Places

An income Generation Supported by PFR

Mr. Ek Bahadur Shahi, migrated from Dhading. He is a leprosy-affected client. His right foot dropped due to leprosy and has ulcer in his leg. He has 2 son, one daughter and a wife. He is a poor and hard working person. He has problem of participation in social activities. Most of the neighbors don't come to his house. He has problem to get work and problem of food arrangement.

He requested to PFR for brick kiln support because he was experienced in that work for a long period of time. PFR supported wood and sand for his business. He managed wages for workers. He got success in his business.

In his kiln, more than three people employed of that community. He expanded his business in another place of Tanahun district. He has no problem in community. The community people accepted him and his business. Now, he has recognized and respected from neighbors. This business helped to improve relationship and reduce of social stigma.

Photo: 5.1

A PALs Employed to Community People in his Business

Table: 5.2

Summary of Acceptance

Activities	**Total respondents**	**Yes**	**No**	**Difference (%)**
Feeling of acceptance of family	59	56	3	94.91
Feeling of acceptance of Client	59	50	9	84.74
Co-worker acceptance of feeling	59	52	7	88.13
Acceptance of Shop-keeper	59	52	7	88.13
Barber acceptance	45	39	6	66.1
Use of Public tap	59	56	3	94.91
Permission to entrance of temple	59	54	5	91.52
Alms acceptance by religious leader	59	55	4	93.22
Use of Public transport	59	53	6	89.83
Involvement of social activities	59	47	12	79.66
Sitting & eating together	59	50	9	84.74
Freely movement in community	59	54	5	91.52
Not staying in leprosy colony	59	52	7	88.13
Movement of neighbors house	59	52	7	88.13
Grand total	**812**	**722**	**90**	**87.38**

The interviewer observed that more than 87 percent clients have no social problems. Still few of clients have problem of socially as well as familial problem of acceptance. Around 12 percents respondents are not accepted due to disability of

leprosy. Like barber for hair cutting, acceptance of alms from priest. Similarly, public transport is not suitable for people with disabled.

Conclusion

Leprosy is a social stigma type of disease. The society is a group of people with sharing each other. In society has different type of activities. More than 87 percent respondents were agreed the community accepted the PALs. Only 13 percent said they were participating due to disability and no property. The PALs who has no property in particular location, he/she may be participated in social activity. Similarly, a few of them were limited the participation cause of caste system. They were asked 14 questions related with “Yes” and “No” related with social attitude and participation. The outcome of 14 questions was 87.38 percent answered they were accepted by community.

The Researcher found that the social rehabilitation is changed the life of people in social participation. Majority of PALs is participating in their social function and community development activities. They have little problem in public places due physical disability. Only approximately ten percent respondents disagreed with easily participation. Change is a gradual process and takes time to change the attitude, knowledge and practices of family and community members. Because most of the rural people are illiterate, poor and less chance of communication such as radio, television and awareness programme. Still rural areas are inaccessible of easy communication media. If we arrange intensive awareness programme at grass root level of people, it will easily reduce the social stigma. Also include the traditional key informants such as priest, traditional healers include in training and awareness programme.

CHAPTER- VI

ECONOMIC REHABILITATION OF LEPROSY AFFECTED PEOPLE

Leprosy affects on nerve system of body. PALs can't do hard and long time regular work, it tends to increase the level of poverty. Leprosy with social and economic problem has close relationship. The leprosy affected people are not able to do hard work and they have to stay long time with rest for treatment. Out of 59 respondents, 3 reported that leprosy was not the cause of economic problem and 56 answered the leprosy creates economic problem to them. Because they couldn't do hard work and should take long time medicine under the supervision of medical person or admit in hospital for long time at initial stage. If the physical situation was worse than they need frequent visit in hospital due to ulcer, reaction and neuritis cases.

PFR supported the PALs with poor and marginalised people of the WDR of Nepal for SER. PFR supported to 34 clients for income generation activities such as carpentry business, livestock production, fruit nursery, tailoring business, vegetable and fruit sale shop, tea shop, TV/radio repairing shop, snacks shop, cycle repair shop, Photo graphic, medical shop and provision shop etc. The amount of support varies from Rs. 2000 to 40700 for a business.

The figure 6.1 shows that among 34 respondents received different type of income generation supports, 9 respondents were received goat keeping, 6 for each activities of buffaloes and tailoring business, two for each Chicken keeping, Pig keeping, Provision shop, Tea with snacks shop and Vegetable & fruit business, one Photography shop, Medical shop and Furniture shop.

Figure: 6.1

Different Types of PFR Support

The economic situation has estimated according to value of stock items. The costs of farm production and livestock have calculated according to stock items and its current value and asking the production quantity and it's cost at local level. The cost of farm production has been calculated in a year the item producing in that farm and it's cost at local.

Mostly the clients were depended on agriculture and livestock farming. There were 60 percent PALs farming agriculture and livestock. Similarly, 12 percent self-employed such as provision shop, tailoring shop, carpentry and repair centers. 4 percent employed by other as regular employee. There were some supports but has failed or didn't continue it. Such as Photography business couldn't succeed because for new person needs to compete with already established businesses. Especially in rural area the people wouldn't like to go and join in new shop owner. Similarly, the chicken keeping business was not continued because of outbreak of chronic and acute disease in poultry house. In addition, Vegetable and fruit business was not succeeded because of rural area very few people would like to buy such items and also rapidly wastes of these items. One teashop was not succeeded due to insufficient market. Without market assessment any kind of business have chance to be failure.

There were 12 percent PALs unemployed due to old age and disability. Out of 12, 4 were students, four were unable to do work due to physical disability and four respondents are due to age factor. The economic situation of client has been improved after getting of PFR support. The 86 percent respondents reported the

economic situation has improved. The 14 percent respondents said still the problem is similar before getting support.

Figure 6.2

Income of Respondents Per Month Per Family

The figure 6.2 shows the level of income of client per month. The PALs income of daily wage range was minimum Rs. 30/- to Rs. 4500/-. Regularly daily wages work was not available. They have not proper record keeping system but they informed orally and it's cost at local level. Among 59 respondents, 13 respondents income was more than Rs. 2000/- per month, other 13 respondents income Rs. 1001-2000/-. Similarly, 10 respondents' income was Rs. 501-1000/- and 9 respondents was less than Rs. 500/-. 14 respondents had no income from his side.

The current sources of income were production of farm and livestock, wages, self-employment business and training fees etc. The costs of livestock were calculated as stock of client. The value of farm production according to annual production and it's cost. The daily wages work was not a regular job it is seasonal. Respondent established own business. The incomes of own business vary from 1000- 20000 per month. The livestock business included goat, buffalo, chicken, pig and ox. Other businesses were tailoring, photographs, medical shop, furniture, fruit & vegetable shop, mobile snacks shop, teashop, bicycle repair shop included under income generation activities. Seven respondents were employed by other organisation after vocational training.

35 respondents replied their current income was satisfactory. Similarly, 24 respondents replied their current level of income not sufficient to them.

6.1 Different Types of Income Generation Activities

PFR provided different kinds of income generation support for client to their economic rehabilitation. The regular work of leprosy affected people physically unable to do hard work compare with other normal people. Due to leprosy and physical disability were reduced the chances to get work. They were not being able to do at same level of work as normal person. If people known about the infection of leprosy, community people won't use them for work in there farm as well as other work. The economic support could be provision shop, livestock raising, vocational training with business, tea shop, mobile fancy and snacks shop, cycle repairing center and television, watch and radio repair center, vegetable and fruit sales shop etc.

6.1.1 Provision Shop

The provision shop is a shop where sales were the daily usable items such as sugar, food items, soap, toothpaste, sweets, brush etc. The provision shop also included moveable shop such as Nanglo business (footpath), doke (bamboo basket) fruit and vegetable business. Investment amount varies from NRs. 1,000-25,000/-. For Naglo-Doko movable fruit and vegetable business running cost is not so much. Out of 59 respondents, 7 received provision shop.

Photo: 6.1

A Tanky/ Ghumti Provision Shop Supported by PFR: Rupandehi

A Success Story of Raj Bahadur Magar

Raj Bahadur is a 26 years male. He is infected with leprosy. He has no visible deformity. When he was getting treatment in Green Pasture Hospital for treatment, he heard about different types of vocational training and income generation activities. He thought that he has difficult to do hard work. Because, he felt his physical situation not so good. He requested to PFR for provision shop. In his community, there was no provision shop. He agreed to run provision shop.

PFR provided NRs. 12000/- to purchase goods of shop. He made a small Ghumti or a Tanky (floor size five square feet, made up of wood and tin roof). PFR provided as grant NRs. 9000/- and as loan NRs. 3000/-. He has refunded the loan at the rate of NRs. 500/- bimonthly interval to PFR. He sold NRs. 300-500 per day. At the time, when we visited in his home he has managed his shop very well.

One day his family member planned to marry him with daughter of relative. His family member asked the relative about marriage and both sides agreed. They didn't communicated about the disease. The marriage programme was finished. After few months some of his relatives communicated to his mother-in-law about the disease. His parent-in-law surprised after knowing about that information, but they didn't believe. His parent-in-law called their daughter to verify that information. When she came in parent's house, she also surprised and she didn't know about the information. Because none of the house members communicated to her. She felt like falling down from height of mountain. She blamed her house members to hiding the disease. Jug Bahadur felt to do suicide, feeling of low self-esteem "atamagalani". What they can do, the time was overt and every events had happened. PFR staff counseled to them about new multi drug therapy he is released from treatment case.

Now, they have a lovely daughter. Both are happy, helping each other. He cares child and managing shop and his wife farm work with kitchen. He is also able to manage the expenses

of marriage and supporting some food items in home. He would like to extend his shop as soon as. In community, most of the villagers come to buy the goods in his shop. Also the provision shop helps his wife to think positively about the disease.

6.1.2 Agriculture and Livestock Training and Support

The economy of Nepal is dominated by agriculture production. Those respondents were illiterate, have good market and available raw materials and physically poor supported by livestock business. The agricultural of Nepal is depended on livestock. Without livestock they can not grow agricultural production. The livestock farming for income generation were included such as buffalo keeping, goat keeping, chicken keeping and pig keeping. The respondents managed their livestock by using of their field products. They were exchanged between crop resides and livestock wastes such as straw with farm compost. So that the livestock is also necessary for field cropping such as compost manure, drought and carrying loads, plough the field. The waste materials of field can supply to feed livestock.

Generally PFR won't support to construct shed or livestock pen, only provided livestock and related training. But in some cases supported other items like feed for pig and chicken. 22 clients have received different types of livestock. Out of 22 agricultural/ livestock based, 10 for goats, 6 for buffalo, 1 for pig, 2 for chicken and 3 for vegetable & fruit business. PFR supported 5 goats for each, one buffalo with straw, one pair piglet with feeds, 10-50 chicken with feed and small amount of money for doko (basket) fruit/vegetable business.

Training is a way to upgrade the current knowledge of respondents. PFR provided different kinds of training related with agriculture and livestock. Training was given before any kind of business. Training such as buffalo keeping, chicken keeping, pig keeping, goat keeping, bee keeping, vegetable farming and micro business training were provided.

A Success Story of Simpa Ahir

Simpa was a 56 years widow woman. She was from rural area of Tarai district. She was affected by leprosy and very poor. She has lost both palms of hand grade two disabilities. She was staying in own community with a small son. She helps to cook food. Life of Simpa was also very complicated. Her adult son was staying separately with owns family because of leprosy. She is very poor.

Especially in Tarai caste such as between Yadav and Ahir, buffalo raising and selling of milk and its products is a major source of earning. She requested to PFR for buffalo keeping business. After a home visit with discussing community members decided to provide buffalo keeping. During assessment community suggested that the community will buy milk of her buffalo. Her grand son supported to buffalo keeping business. PFR supported NRs. 18000/- for a newly calved young buffalo with calf and fodder.

The milking buffalo daily provided four liters milk and sold in nearest market at the rate of Rs. 20/- per liter. Gradually it helps to change the economic status and getting better life. She sold milk in teashop close to her village. There was no problem to sell milk and accepted her adult son.

It shows that in her community they accepted the people affected by leprosy. Teashop is a place where majority people share each other events and know very well. Most of her time spent to care of buffalo and selling of milk. Her grandson is helping her for cooking food.

Photo: 6.2

A Buffalo Keeping Business Supported by PFR: Nawalparashi

6.1.3 Vocational Training

The vocational training is a major activity of socio-economic rehabilitation. The training increased the knowledge of individual and made them independent. Some of the leprosy affected people have physical disability some of them not able to continue previous work. Woman became financially independent after getting the vocational training. Before vocational training, an assessment related with vocation carried out to know the gap or level of person ability. The leprosy-affected people lived in extreme poverty and may be excluded from their previous employer or denied access to their former market. The physical impact of leprosy made it impossible to continue previous occupation. Vocational training is an opportunity to earn income to be independent in the process of socio-economic rehabilitation. The vocational assessment helps to find out suitable vocation according to client's situation. The training helped them to gain new skill of clients.

The duration of training varied from one month to eighteen month depended on types of training and the level of clients' physical and mental situation. Given vocational training were tailoring training, weaving, photographic, watch/TV/radio/cycle repair, hair cutting, metal wielding, furniture, Community Medical Auxiliary (CMA) and Auxiliary Nurse Mid-wife (ANM). The training could be at community based or center based. Most of the trainees started their business after training.

Out of 59 respondents, 10 received vocational training. Among 10 respondents, 5 received tailoring training with business, one carpentry business, one photographic

training with business, two Community Medical Assistant with medical shop, one Auxiliary Nurse Mid-wife and one clients weaving training with business.

Photo: 6.3

A Tailoring Training Supported by PFR: Chitwan

6.2 Improved in Other Areas

The table 6.1 shows the outcome of PFR given support used in more than 14 different areas. Mostly the support helped to fulfil the basic needs, education for children, increased social relationship, improve skill, increase income and improve health by using product of given support. Few of the respondents answered in more than two areas have improved. The list of areas as follows:

Table: 6.1

Improved in Other Areas

Improved areas	**Frequency**
Food and house	40
Drinking water	6
Expanded the shop	5
Education	4
Increased income	3
Self-employed	2
Compost	2
Improved Health	2
Tailoring trainer	2
Business experience	1
Straw	1
New machine	1
Marriage	1
Released land from bank	1

6.3 Different Ways of Socio-economic Rehabilitation

There were different ways of socio-economic rehabilitation of PALs. The table 7.1 shows, out of 59 respondents, 42 respondents suggested that the vocational training with self-employment is the best option for socio-economic rehabilitation. Six respondents said to arrange employment opportunity, three respondents agreed each of the income generation and institution based rehabilitation. Similarly, one for each suggested for keeping in leprosy colony with facilities and includes in government policy for SER.

Table: 6.2

Different Ways of SER

Ways of good Rehabilitation	**Frequency**	**Percentage (%)**
Vocational training with self-employment (VTB)	42	71.18
Arrange employment opportunity (AEO)	6	10.16
Income generation programme (IGP)	3	5.08
Institution based rehabilitation (IBR)	3	5.08
Providing living subsidy (PLS)	3	5.08
Settlement in Leprosy colony with facilities (SLC)	1	1.69
Other (include in government policy) (IGP)	1	1.69

6.4 Methods of Awareness Raising

The respondents were suggested different ways of awareness raising for the people. If people are aware about the leprosy, it reduces disability caused by leprosy and reduces the social stigma. Awareness programme related with leprosy, prevention and early detection is most necessary for community people. Than PALs will get social dignity and social respect. The respondents said it should be focused in rural areas. The methods are as follows:

- Rural Radio program

- Television programme of Success story of Socio-economic rehabilitation
- Include in course of school books
- Publication in Local magazine about leprosy
- Distribution of awareness Poster/Pamphlet
- Developing film
- Street Drama
- Positive Extension
- Counseling PALs, their family and community
- Discussion in rural community
- Regular Home visit
- Seminar/workshop

6.5 Information Collected with Key Informants

Thirty-seven key informants participated of surrounding supported clients of PFR. Among the key respondents participated in this interview, 8 were teachers, 6 Village Development Committee ex-members, 16 neighbors, 3 Women Group members, 3 Female Community Health Volunteers and 1 the organisation member.

Mostly the key informants said the knowledge, attitude and practices of community have been changed about leprosy. They did not agree the communities to behave like segregation and isolation. Most of the PALs contributed in community for development activities such as construction of road, drinking water system, forest conservation, and involvement in different committee as general members and some in key post. They suggested leprosy patients to go in hospital that has ulcer. Those PALs having seeping ulcer of leprosy clients hated by community. The community referred the patients to hospital for early treatment. Most of the key informants don’t know other leprosy-affected people around their periphery.

They were not aware about the available activities for leprosy-affected clients and their children. Most of the PALs were invited in social recreation activities and functions. The respondents agreed that the attitude of people has been changed and they were positively behaving to them. Mostly poor people were known in community as affected by leprosy but the communities didn't know the rich person who has affected by leprosy because they were able to manage their treatment in another hospital or other city or neighboring countries. The rich leprosy affected people would able to manage the socially and economically.

Rich people go to another place in India or Kathmandu for treatment but poor can't afford bus fare and other expenses for frequent visit. So that social stigma relates with poor and marginalised people. They appreciated the PFR support for leprosy clients.

6.6 Rehabilitation Services Availability in the Study Area

Very little number of organisations launching socio-economic programme for leprosy clients. Mainly, INF has been working since 1952 A.D. for the leprosy affected people of Nepal. Similarly, Nepal Leprosy Relief Association (NELRA) has been supporting some vocational training, settlement and giving living subsidy for specific clients of limited in members. There were many organisations that work for the disabled people based on community-based rehabilitation. So that disabled organisation only includes that person who has visible disability within a limited area of a district.

In Nepal, two leprosarium were established in 1857 A.D. at Khokona of Kathmandu and Malunga of Syangja districts. But now a day there is no leprosarium in Syangja district. These leprosariums were managed by NELRA. Few years ago, a resettlement of leprosy colony was organised by NELRA in Kaski district of

Lekhnath Municipality and Pokhara municipality 18 was named as 19 houses (Unnais ghare), 6 houses (Chha ghare) and 12 houses (Bara ghare) respectively. NELRA provides one-year vocational training related with metal craft and wooden craft and supports the limited number of students for their schooling.

There were many organisations working for the people with disable people of the Western Development Region of Nepal. Mostly they are working in certain periphery of districts. They do not cover whole of the district. These programs are not working with non-visible disability with leprosy. Leprosy is related with stigmatize disease of social problem. PFR is an organization specially giving priority for leprosy-affected client and their family members of socio-economic rehabilitation.

6.6.1 List of Organization Working for Disabled People

There are few organisations working in the Western Development Region of Nepal for focusing people with disability of the community-based rehabilitation. They are as follows:

Table 6.3

Name List of Organization

Name of organization	Address	Activities
Gaja Youth Club (GYC)	Buglung municipality 2, Mahendrapath, Dhaulagiri Telephone number 068-520398.	⁃ Voice for Education ⁃ Community approaches to handicap in development (CAHD)
Disable Upliftment Society (DUS),	Gajedaha 2, Kapilbastu, Telephone number 076550079	Community based rehabilitation for PWDs.
Sunghava Community	Rudhrapur, Rupandehi	PWDs, PALs and HIV/AIDS

Development Center (SCDC)		(Rudhrapur, Bishnupura and Sandhi).
Partnership for New Life(PNL)	Butwal, Rupandehi, PO box 2, Telephone number 071546124.	Physical rehabilitation of disabled people, social rehabilitation, income generation of disabled and leprosy affected people.
Community Based Rehabilitation Service (CBRS)	Pokhara, Nayabazaar, Kaski Telephone number 06158250/537326.	Kaski and Syangja districts
Sunwal Community Development Center (SCDC),	Sunwal 4, Nawalparashi, Telephone number 078570239/570141.	Sunwal VDC
Disable Rehabilitation Center Nawalparashi (DRCN):	Nawalparashi, Shivamandhir 3, Kawasoti, Telephone number 078540414/575110	Agyoli, Pithauli, Kawasoti, Pragatinagar and Dibyapuri VDCs
Sundari Community Forestry	Amrapuri VDC 1, Nawalparashi, Telephone number 078545237.	Forest user group supporting to PWDs
Matri Community Development Forum	Gaindakot 4, Nawalparashi.	Gaindakot and Ratanpur VDCs
Arughat Bagaincha Church (ABC)	Arughat Bagaincha Church, Aruchanaute 1 VDC, Gorkha, Telephone number 9846068695.	Thumi VDC of Gorkha
Rehabilitation Center for Disabled (RECED),	Byas 10, Damauli, Tanahun, Telephone number 065561175.	Byas Municipality of Tanahun
Creative Disabled Society (CDS),	Lekhnath, Kaski district, Telephone number	Lekhnath municipality of Kaski and Dulegauda VDC

	061561374.	of Tanahun

- Gaja Youth Club (GYC), Baglung: GYC was established in 1996 AD and involving in activities for different able people. It has two projects such as "Voice for Education" and " Community approaches to handicap in development (CAHD)". The area for this project is running in Baglung and some VDCs of Kaski district.

- Disable Upliftment Society (DUS), Kapilbastu: It was established in 2056 BS as an NGO and working in 8 VDCs.

- Sunghava Community Development Center (SCDC), Rupandehi: It was established in 2052 BS situated in Rudhrapur VDC of Rupandehi district. The activities focused for PWDs, PALs and HIV/AIDS. The working area of SCDC is Rudhrapur, Bishnupura and Sandhi.

- Partnership for New Life (PNL), Rupandehi: It was established in 1999 and situated in Butwal, Rupandehi district. PNL is mainly concerned with physical rehabilitation of disabled people, social rehabilitation, income generation of disabled and leprosy-affected people.

- Community Based Rehabilitation Service (CBRS): CBRS is working for and with disabled people and their families, and the wider communities. The working area of CBRS is Kaski and Syangja districts.

- Sunwal Community Development Centre (SCDC), Nawalparashi: SCDC was established in 2058 BS, working in Sunwal VDC of Nawalparashi for disabled people and community development activities.

- Disable Rehabilitation Center Nawalparashi (DRCN): DRCN was established in 2058 BS working for people with disable. It has been working in Agyoli, Pithauli, Kawasoti, Pragatinagar and Dibyapuri VDCs of Nawalparashi district. DRCN working as principle of CAHD approach.

- Sundari Community Forestry, Nawalparashi: The forest user group aims to conserve and use of forest products. This Forest user group supported to PWDs and inclusion of mainstream of development.

- Matri Community Development Forum, Nepal: It was established in 2059 BS. The working area of Maitri is Gaindakot and Ratanpur VDCs of Nawalparashi district. This organization is working with disabled people.

- Arughat Bagaincha Church (ABC), Gorkha: ABC was established in 2052, situated in Aruchanaute VDC of Gorkha district. It is a Christian community based organization working for the PWDs. ABC is working in Thumi VDC also.

- Rehabilitation Center for Disabled (RECED), Tanahun: RECED was established in 2059 BS, in Tanahun district. RECED is a disabled people organisation working for complete participation and developing leadership of PWDs. RECED working for the right and advocate on the behalf of PWDs. It has been working in the Byas Municipality of Tanahun district.

- Creative Disabled Society (CDS), Kaski: CDS was established in 2056 BS and located in Lekhnath Municipality, Kaski. The working area of CDS is in some wards of Lekhnath municipality of Kaski and Dulegauda VDC of Tanahun districts. It was registered as an NGO working for disabled people.

6.7 Observation of the Researcher about Client Situation

The Data Enumerators were ranked the socio-economic situation of respondents. The table 7.2 shows among 59 respondents, 12 respondents were no disable but at initial stage they had social and economic problem. At such stage clients were psychologically depressed. The interviewer realized for 8 respondents did not have disability, social and economic problem. 21 respondents had no disability but they were in need of socio-economic changes. Similarly, 5 respondents have disability but no need of socio-economic rehabilitation. Out of 59 respondents, 13 were having disability with social and economic problems. None of them is at vulnerable stage of disability, social and economic rehabilitation. Out of 59 respondents, 21 have no disability but they need socio-economic rehabilitation. They are poor and unable to do hard work for food.

Table: 6.4

Conclusion of Data Enumerator

Conclusion of interviewer	**Frequency**	**Percentage (%)**
No disability but at initial time have social and economic problem	12	20.3
No disability, social and economic problem	8	13.6
No disability but have socio-economic problem	21	35.6
Have disability but no socio-economic problem	5	8.5
Disability, social and economic problem	13	22.0
Disability at vulnerable stage	0	0

Conclusion

PFR supported income generation, vocational training with business, agricultural and livestock training with business as for raised the income of the respondents. Income generation activities were not sufficiency in some clients. Some of IG activities were directly affected on client's life. Few respondents were using money for children education. Two respondents have been giving tailoring training to community people.

If the person has direct authority and sufficient property, there was less social stigma. Also the given support of PFR decreased more or less the social stigma. Similarly, PFR reached close to poor as their targeted people. The highest numbers of respondents were suggested to provide suitable vocational training with business as a good way of SER. So that the Data enumerator suggested, still leprosy-affected people were poor and they need some economic support too.

Similarly, the Key informants of community suggested for vocational training with suitable business a good way of rehabilitation. Most of the key informants said the knowledge, attitude and practices of community people have been changed on behalf of leprosy disease and its beliefs. In addition, the interviewer suggested that 21 respondents were not physical disability but need of socio-economic rehabilitation. Interviewer suggested 13 respondents who have disability with need of social and economical rehabilitation.

CHAPTER- VII

SUMMARY, CONCLUSION AND RECOMMENDATION

7.1 Summary

Leprosy is a major public health disease all over the world. This is socially stigmatized disease. The Government of Nepal has targeted to reduce prevalence rate less than 1 case per 10000 populations in Nepal by the end of 2005. The latest data (F/Y 2062/63) has shown the prevalence rate per 10000 is 1.14 in the Western Development region of Nepal. The medical treatment is available in all health post centers and hospitals at free of cost. In visible disability, the social stigma is higher in the Grade 2 and 1 disability.

Social stigma is the cause of isolation and segregation of leprosy clients. Segregation limits the participation in social activities. Segregation is disintegrating the society. In the process of SER, the social problem creates limit the participation to get works; it makes a person poor. Leprosy with poor people needs accommodation, acculturation, assimilation, re-integration and socialization of SER. In Nepal, there are more than11 INGOs working for leprosy affected people. In the WDR, INF is the major organization for leprosy-affected people. Similarly, NELRA is another organization working for the leprosy people.

During 2000 to 2004 the total leprosy clients were 155, sampled respondents 77 out of 155, interview carried out with 59 respondents. The respondents were participated from 13 districts. The primary data were collected with the clients and secondary data from PFR. The overall views about leprosy on knowledge, attitude

and practices were collected with female community health volunteers, teachers, VDC members and neighbors.

The respondents represented from 35 VDCs and 6 municipalities. The average household size was 4.33 of the respondents. The age ranges between 5-61 years old. The highest numbers of respondents were age of 41-60 years old that was 25 out of 59. Similarly, male and female ratio was 2.47:1. The people accepted different religious such as Hindu, Christian and Buddhist. The respondents were majority of Hindu religions. Among 59 respondents, 16 were upto high school levels of education, 16 were just literate and 27 were completely illiterate. Leprosy with divorced also related each other as social stigma. There were 7 respondents divorced, out of 7, 4 were female and 3 male.

Disability is graded according to WHO in three levels. That is 0,1 and 2 on the basis of limitation. The respondents were Grade 2 disability of eyes of 2 respondents, hands of 13 respondents and feet of 24 respondents. Similarly, Grade 1 disability was on eyes of 15 respondents, hands of 11 respondents and feet of 9 respondents. Grade 2 and 1 has high social stigma than grade 0 disability.

The study area is the Western Development Region and including a district of the Central Development Region of Nepal (Chitwan). The castes of respondents were Gurung, Magar, Brahamin, Chetri, Bishwakarma, Pariyar, Sarki, Baram, Kumal, Sunar, Yadav, Chaudhary, and Nepali. There were health services available in 4099 health centers. The leprosy-affected respondents were informed, they faced more than17 different health problems such as allergy and paralysis was the biggest health problem. Similarly, second category was tuberculosis, pain in legs/hands and jaundice. Third category headaches body vibration and body swelling. Fourth

categorized Soriasis, fever, respiratory disease, blood pressure and epilepsy. Fifth categories cancer, anemia, sun itching, ulcer, diabetes and cough.

The houses of 71 percent respondents have tin roofed with stone/brick wall. 22 percent have thatched roof and 7 percent staying in rented house. PFR supported 26 respondents to construct or repair their house.

Leprosy affected people, as possible would like to hide it from family, co-worker and community. Mostly PALs have fear of breakdown the relationship and rejection from house and limit the participation. People easily known to Grade 2 disabled people. But Grade 1 and 0 are difficult to distinguish the disability. Out of 59, 51 respondents known by community and 8 respondents were unknown case in his/her community. But in family almost known them as leprosy. 11 percent respondents don't know, 14 percent believed on result of previous life and bad wishes of God. And 41 percent agreed it is a disease. Family members of 58 respondents, neighbors of 31 respondents and society members of 21 respondents accepted the leprosy clients. The respondents felt of acceptance by family, co-workers, shopkeeper, barber, public tap, temple entrance, religious leader acceptance alms and using public transport. It is positive sign of change in social attitude and practices.

90% PALs were living with own family members and 8.5 percent live separately. Family members asked 45 respondents (76%), when they make a new decision. From the respondents views, the community people, 29 percent believe it is causes of God and highly transmittable. 46 percent think it is a curable disease and shouldn't segregate it. Most of the respondents involved in social activities, sitting together with non-leprosy people and freely move with their children and co-workers in own community. 87.38 percent respondents agreed on the acceptance of community members in social function and no limitation for communal works.

Social and economic problems are closely related with leprosy. Social stigma limits the person to participate in society. The limitation of participation creates economic problem by unemployment. 95 percent respondents said leprosy is the cause of economic problem because the affected people need to stay in hospital for long time and during treatment time they have to take rest.

PFR supported income generation for 15 percent clients to keep goat keeping, 10 percent buffalo keeping, 10 percent tailoring business, 3 percent of each chicken keeping, Pig keeping, provision shop, Tea with khaja (snacks) shop and Vegetable & fruit business, two percent of each Photography shop, Medical shop and Furniture shop. 76 percent respondents were earning per month ranges Rs. 500-more than 2000/-. Only 24 percent respondents were not earning as employing in others. More than 60 percent respondents were earning through livestock and agricultural production.

The vocational training was the major items of SER support. There were 10 respondents received training varies from one month to 18 months. 5 tailoring trainees were doing business in own community. Two trainees providing training to community people. Another successful business was carpentry business. Two trainees of CMA and ANM have got employment in different organisation. One CMA established a successful medical shop in own community. The photography and weaving trainees couldn't continue of their business. The respondents informed the incomes of business were used in more than 14 different areas.

In WDR of Nepal there are many organisation working for the disabled people. INF and NELRA especially included Socio-economic rehabilitation for leprosy clients. Mostly the organization working in a certain parts of the district. The 71 percent

respondents suggested vocational training with business based option of SER. Similarly, the respondents were suggested 12 different options to create awareness in family and community about leprosy. Meanwhile, the community key informants suggested suitable training with business a good option of SER. There are many organisations conducting their activities for disabled and none disabled people but not included to them. Similarly their coverage is uncertain part of district headquarters. There were no programmes specially focusing leprosy clients for socio-economic rehabilitation.

The Data Enumerators suggested 25 clients were no need of socio-economic rehabilitation. Still some kind of economic support is necessary for them because of disability and cause of becoming old age. Similarly the community people appreciated socio-economic rehabilitation programme focusing for leprosy clients.

7.2 Conclusion

Leprosy is a stigmatise disease leading problem related with social and economic perspective. The main objective of this study was to know the effectiveness of socio-economic rehabilitation in the Western Development Region of Nepal carried out by Partnership For Rehabilitation (INF). The SER helps them to find their place in community. However the findings of this study, giving a positive sign of decreasing social stigma. 87.38% respondents agreed the acceptance of society in social activities. This indicates that the social participation is increasing in social function. However, in the case of divorce comparison between female was higher than the male. As suggested by SER principle the female leprosy clients should be more focused for socio-economic rehabilitation. The female leprosy needs more social economic rehabilitation to reduce social stigma.

Similarly, 12.62% respondents agreed for the supporting of the existence of social problem. 95 percent respondents were staying with own family members. Also, family members asked 91 percent respondents during making any new decision at home and 6% respondents were not at decision making level stage. 9% respondents were staying as single and 3 percents (only one client) said never asked for any kind of decision. The relationship among the family members with leprosy clients is continuously increasing towards acceptance of family members.

The leprosy-affected people used the support in more than 14 different areas. Most of the respondents were helped them to fulfil the basic needs of clients (food and clothes), education for their children, helped to increase the social relationship with community people and own relatives. The given support helped them to improve the vocational skill of clients. In some respondents, the given support used to feed own children and clients to be better health.

Similarly, the support increased the level of income of clients. Few of them answered in more than two areas were improved. Some respondent's knowledge of business was increased, because it is most necessary to a person before starting any kind of business for success of his business. Not only the selling animals or milk but also other wastes bi-products of animals such as compost use in farm to increase the products of farm. In addition, two respondents became tailoring trainers to the community people. One respondent used the profit of business to own marriage. Economic factor is also playing a major role to get status in family and community. Poor have low status compare to rich. Also disintegration of the poor is higher than the richer. The level of participation is poor in the poor economic situation in social activities.

The current situation of the given support of 31 respondents were found at usable stage, two of them using drinking water system, 14 respondents were having livestock, 6 were using their machine and two of them for training center. One of each respondent was running wood furniture, one wheel rickshaw and medical shop at good condition. The three respondents were not succeeded such as one of each business mobile vegetable sale, pig business and teashop. These failure respondents have weighing scale, one only pigpen and one completely closed provision shop.

The perception of the community people on behalf of leprosy has been changing the attitude of people positively. 46% respondents' perception was that leprosy is the causes of bacteria and could be in all kind of human being. There is no specific basis to infect person to be leprosy such as colour of skin (Black & White), caste (High & Low) and economic condition (Poor & Rich) of people. Only 2 percent said leprosy is highly transmittable and 27 percents said it was the result of past life of a mis- work. Still there were 25 percent respondents who don't know the causes of leprosy.

Most of the respondents were happy if the non-leprosy people sit together, shake hands, eat together in social activities and invite them or attend in their social and community activities. The respondents agreed on the non-leprosy and leprosy affected people use same public places and resources. It was sign of decreasing the social stigma and increasing the participation.

The respondents, Key informants and the Data enumerator highly agreed on the suitable vocational training with business as the best way of socio-economic rehabilitation. Also, the Data Enumerator suggested the leprosy clients with non-visible disability clients the need of socio-economic rehabilitation. Similarly, many organizations were working for the disabled people and partly covered the areas of

district in their program. Only Direct Client Assistance, PFR has been including such clients in their plan. PFR is mobilizing the client, family and community at whole process of SER.

The involvement of community people and family members of the clients during rehabilitation process sustain the program and reduce the social stigma. The life of survive of PALs becomes easier in comparison to previous stage. This study helped the researcher to increase the knowledge about SER and contribute about the concept of social rehabilitation. The researcher knew the past practices of socio-economic rehabilitation in PFR.

7.3 Recommendation

Change is a continuous process. Everywhere in the world change is occurring. There are many factors of changing process. Similarly the degree of changes varies from place to place, person-to-person, events and events and so on. Leprosy disease is familiar as a highly stigmatized disease. It is also known as oldest disease in the world.

- The word “Kustha” in the holy books explained as punishment of God and result of past life of misdeed. The priest should give the scientific causes of leprosy, ways of transmission and availability of its treatment. The community people highly believe them and they are the key people of the community. They are religious leader and guide the society in most of social activities.
- Leprosy is highly related with social stigma. It would be better to attach with skin disease rather than deformity and fearful disability.
- Awareness is most important to reduce social stigma. The respondents suggested more than 12 different ways of awareness rising at grass root level of people with easiest as well as local languages. All the awareness programs should be

focused on the grass root level of the community. Mobilize the local religious leader and traditional healers to create positive thinking.

- Mobilize the leprosy-affected person in a good way to create self-confidence for unknown/known clients.
- Those people affected by leprosy that have no deformity and disability don't like to disclose about the infection of disease. This is right of the individual. If we disclose about the disease, it may hamper in his/her life and family members. When we visit in his/her community should always ask about the cases of known or unknown about the disease or take permission if we would like to disclose about him/her.
- Those people, who have Grade 2 and 1 type of disability, such people suffer high social stigma. So early detection and timely treatment is most necessary for leprosy-affected people. Still in remote part of district people are unaware the cause, sign and symptoms of leprosy. Also they don't know what are the preventive methods.
- Grade 0 disabled people have no visible disability and no problem after getting treatment. But they may have problem of doing hard work.
- Reason behind being disability is the clients who should come in hospital at regular interval. In such cases the poor and remote areas discontinued or irregular of taking medicine because the poor and remote areas PALs have problem of fare and accommodation. The leprosy disease can make person poor. Example: If a client should monthly visit in hospital from remote part of Gorkha or Baglung or Gulmi or Arghakhachi than they have to pay at least NRs. 1000/- bus fare two way and food and accommodation NRs. 600/- with time 3-6 days. How can they mange it properly for their good health? In such situation clients should get regular travel and accommodation expenditure after assessing of socio-economic situation of client.

- Special care of the client, family members and community should be focused on self care of visible deformity, disability, anaesthetic hands and feet for woman, old people and children with poor condition.
- The vocational training could be a major activity to be independent for a client for socio-economic rehabilitation.
- At the time of socio-economic rehabilitation client should be included, family and community during assessment, planning, and implementation and follow up time. The plan should be participatory, sustainable, transparent, accountability and integration in society.
- Some of the income generation activities were unsuccessful. A good assessment of market, availability of raw materials, past experience, social acceptance, physical viable, technically suitable, financially affordable, support of family and community support or situation is necessary.
- Education is a major part to reduce the social stigma. The researcher found higher literacy lower social stigma. The course curriculum should include a topic of about leprosy.
- Divorce case is higher in female than male. The rights of female on property, education, getting children should support to them.
- Medically and SER should be foresighted for the uncorrectable mistake. The decision of stopping getting children was not a good foresightedness. E.g. Family planning of leprosy clients in 19 home.
- Not to isolate them as making leprosy colony but include in mainstream of development activities.
- Adoption of inclusionary policies and practices that foster inclusion of disabled people in mainstream economic participation
- Legislation promoting equality and full participation implemented through enforceable laws.

- Medical or physical fitness for employment should be replaced with the individual's capacity to work when given the access they need.
- Government should provide subsidies available to help employers make work environments accessible.
- There should be mechanisms to prevent discriminatory remuneration practices.
- Information regarding job vacancies, training etc. should be accessible to all disabled people. A recruitment allowance should be paid to cover travelling expenses and cost of lodgings to facilitate participation in the recruitment.
- Employers should include a disabled representative in the recruitment process.
- Peer should be provided to disabled people to enhance their self-esteem and give them confidence to enter the job market.
- All disabled people should have equal opportunities to gain promotion based on their education, training, skills, experience and merit.
- The government should provide subsidized training and education for all disabled people in an environment where job-based training is available.
- Disabled employees should be provided with allowances to cover the cost of aids, adaptations and assistance.
- Employers should offer flexible working hours to disabled employees and other employees if appropriate.
- Employers should educate and train the staff about understanding of disability.
- Employers should prioritize making work environment accessible, provide accommodation for disabled employees near the workplace and accessible transport for easy access to workplace."
- The income generation is most necessary to identify proper business for particular person. The people who have anaesthetic and frequent reaction have also problem of regular visit in hospital and need some vocational training with business.

- The PALs have problem of settlement for housing. They are not able to afford to make and repair their houses.
- The SER strategy follows the global strategy for further reducing the leprosy burden as sustaining leprosy control activities. There are four key message for the general public, which can be expressed in many different ways:

- Curable- leprosy is an infectious disease but the risk of developing the disease is low. It can be cured with drugs that are widely available and at free-of-charge.

- Early signs- of leprosy is pale or reddish skin patches, with loss of sensation: early detection with appropriate treatment helps to prevent disability from leprosy.

- No need of fear- The disease can be managed just like any other disease; affected people should not suffer any discrimination. Treated persons are no longer infectious.

- Supports- Affected people need the support and encouragement of their family and community, firstly, to take the MDT and any other treatment as prescribed, and secondly, to be able to live as normal a life as possible.

Definition of term

- **Rehabilitation:** Refers to bring at previous condition
- **Socio-economic rehabilitation:** Person or family members have less opportunity to adjust in society or to be better economic situation. Due to social and economic poor situation, person will be rejected from his/her community. For this they need support for socio-economic is called socio-economic rehabilitation.
- **Vocational assessment:** It is a kind of process to identify the interest and ability.
- **Vocational rehabilitation:** The person after infected by leprosy can not continue his skill or profession or job at the same level or situation. Either it should change new job or need some modification with or without supporting tools is called vocational rehabilitation.
- **People affected by leprosy:** The person or the family members affected by leprosy.
- **Social stigma:** An attitude in society to reject the client or family members from society for any kind of social contact/ relationship.
- **Social change:** Every society cannot stand fix. It happens everywhere but the rate is varies from place to place. It is changeable. Social change is the evolution of culture over time. The society change due to economic, migration, political, religious, and technical. There is always tearing and wearing and form new structure/shape.
- **Economic change:** The purchasing and saving abilities of person has been increased.
- **Social inclusion:** The removal of institutional barriers and the enhancement of incentives to increase the access of diverse individuals and groups to development opportunities.

- **Incidence:** The annual finding rate or the number of new cases of leprosy diagnosed each year.
- **Prevalence:** The estimated population of people who are managing leprosy at any gave time.
- **Deformity:** Secondary structural changes of the eye, hand or foot resulting from impairment of sensory, autonomic and /or motor nerve function: joint stiffness, bone absorption, and muscle imbalance such as 'clawing".
- **Disability:** A loss or restriction of functional ability or activity as a result of impairment of the body or mind.
- **Handicap:** Partial or total inability to perform a social, occupational or other activities that the affected person wants to do.
- **Impairment:** Any loss of abnormality of psychological, physiological, or anatomical structure or function (WHO, 1980).]
- **Occupation:** A set of activities centered on an economic role and usually associated with earning for living.
- **Rifampicin:** An antibiotic drug, which kills the leprosy germs.
- **Status:** A defined position in the social structure of a group or society that is distinguished from and at the same related to other positions through its designated rights and obligations.
- Prevalence rate

  $$\frac{\text{Number of leprosy case registered for treatment at a given point of time}}{\text{Number of new cases detected}} \times 10000$$
- **Anaesthetic:** An agent that reduces or abolishes sensation, affecting either the whole body or a particular area or region.

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APPENDIX I

QESTIONAIRE

Questionnaire/Interview guide or Instruments

1. ID number
2. Name
3. Gender: a) Male b) Female
4. Citizenship: a) Yes b) No
5. Date of birth/years
6. Address

   a) High hill b) Mid hill c) Terai
7. Ethnic/Ethnicity
8. Religion

   a) Hindu b) Christian c) Muslim d) Buddha e) others
9. Education

   a) Illiterate b) Primary c) High school

   d) Degree course e) Vocational training
10. Marital status

    a) Unmarried b) Married

    c) Separated d) Widow d) others

10.a If unmarried reason

a) Due to disability b) Due to disease c) Other reasons

10.b If divorced reason

a) Disease b) Due to disability c) Other reason

11. Children/Family members

S.N.	Name of children	Gender	Age

12. Types of Leprosy bacteria

a) Multi-bacillary b) Pauci-bacillary

13. Disability grade (0, 1, 2) (by World Health Organisation)

13.a Eyes	I. 0	II.1	III. 2
13.b Hands	I. 0	II.1	III. 2
13.c Feet	I. 0	II.1	III. 2

14. Generally which types of other disease affect to leprosy clients?

a) _____ b) _____ c) _____

15. Whether he/she is known as a case in

15. a) Family	I. Yes	II. No
15. b) Community	I. Yes	II. No
15.c) Employer & colloquies	I. Yes	II. No

16. Current sources of income

16.a Farm productions	muri/quintal/bora	Rs.
16.b Livestock	numbers	Rs.
16.c Daily wages	day/month	Rs.
16.d Employment		

16.e others		

17. Occupation

a) No b) Farm labour c) Industrial worker

d) Self-employment e) Regular employment

18. If not getting income, reason for not working

a) Student b) Unable to get a job due to disease

c) Unable d) could not get a job e) Old age

19. Whether receiving any securing benefits/service from government

a) Yes b) No c) Others

20. How many/much items/money did you get from Partnership For Rehabilitation/others?

20.a New house with land	
20.b New house	
20.c Provision shop	
20.d Livestock	
20.e Vocational business	
20.f Paid loan	
Others	

21. Did you get any vocational training from any other organisation

a) Yes b) No c) Not attempted

22. If yes, name of organisation, types and duration of training

……

23. What did you do before getting support?

a) Income generation programme b) Business c) nothing

24. What about your house

a) Covered with plastic sheet b) thatch roof c) tin roof

d) Tin, stone, cement e) Tin, cement, clay

25. In which areas have been improved

a)_____ b) _____ c) _____

26. What is the present situation

a) ……. Cash/ credit

b) ……. Nos.

c) …….. Stock quantity

27. After getting support, situation is

a) Improved b) become worse c) not changed e) Not known

28. After getting support what is the Income per month/day (in Rs.)

a) Nil b) Up to Rs. 500/- c) Rs. 501-1000

d) Rs. 1001-2000 e) more than Rs. 2000/-

29. Whether he/she is economically self-sufficient

a) Yes b) No

30. What are the reasons behind changing your life?

a) Own efforts b) family support

c) community support d) others

31. Whether he/she is living in a leprosy colony/asylum

    a) Yes b) No

32. Housing

    a) Lives with family b) Separately c) No family due to disease

33. Does he/she attend social functions

a) Yes b) No

34. Did you sit in social functions equally with others for food

a) Yes b) No

35. Does the shop keeper do good behavior during visit his/her shop

a) Yes b) No

36. Does he/she go to hotel

a) No habit b) Yes c) No

37. Hair cut difficulty in barber's shop

a) Yes b) No

38. Does he/she have problem in public tap?

a) Yes b) No

39. Does he/she go to temple

a) Yes b) No

40. Does the Pujari accept given fruits, grain, and money?

a) Yes b) No

41. Does he/she has normal sexual relationship

a) Yes b) No c) Does not arise

42. In your family, are they ask anything regarding house works

a) Yes b) sometime c) no d) no answer

43. Does he/she move freely with children

a) Yes b) No

44. Using public transport system without problems with staffs of bus and passengers

a) Yes b) No

45. Does he/she move freely with community

a) Yes b) No

46. Does he/she move freely with Employer/co-worker

a) Yes b) No

47. Does he/she feel that he/she has social acceptance in the family

a) Yes b) No

48. Does he/she feel that he/she has social acceptance in the community

a) Yes b) No

49. Does he/she feel that has social acceptance in the Employer/co-worker

a) Yes b) No

50. In his/her daily living

a) Independent b) Dependent c) Semi-dependent

51. Does he/she think whether the disease/deformity produces

51.a Social	I. No	II. A few problem	III. Many problems	IV. Social rejection
51.b Economic	I. No	II. A few problem	III. Many problems	IV. Social rejection
51.c Family	I. No	II. A few problem	III. Many problems	IV. Social rejection

51.d Neighbors	I. No	II. A few problem	III. Many problems	IV. Social rejection

52. What do you think the reason being leprosy patient

a) Don't know b) Due to result of previous live

c) God wish d) Similar to other diseases

53. What other people think about your disease

a) It is transmittable, so the person should stay away of that community

b) It is curable, so send him as soon as in hospital for treatment

c) It is result of past life, because he did misshapen

d) We should help him to include in our community, because it is a disease can be anyone of us

e) Others

54. What do you feel, when other people sit with you, eat together and sake hands

a) Internally feel uneasy b) Become happy

c) Encourage d) Feeling of love

e) Feeling of external sympathy f) Others

55. Does he/she come and go to the neighbor’s house

a) Yes b) No

56. What do you feel about problems does your family facing

a) Getting trouble in own community

b) Community people don't want to meet your family

c) Sharing family members like other community people

d) Others

57. Do you like to help or did you help other people of community

a) Sometime b) usually c) never

58. Do you feel other people respect to you

a) Yes b) sometime c) no d) confuse

59. In your house's kitchen, your eating utensils keep together with others members utensils

a) Yes b) sometime c) no d) no clear answer

60. What do you think, how PALs can be rehabilitated good way

a) Income generation activities
b) Institution based rehabilitation
c) Getting skillful training and placement
d) Employment opportunities
e) Subsidy for food, accommodation
f) Keep in separate colony of PALS with facilities
g) Others (e.g. government policy)

61. The below mentioned points are agree or disagree

61.a Leprosy is a Social problem	I Completely disagree	II disagree	III No response	IV agree	V Completely agree
61.b PALs needed Socio-economic rehabilitation	I Completely disagree	II disagree	III No response	IV agree	V Completely agree
61.c Leprosy is Caused by	I Completely disagree	II disagree	III No response	IV agree	V Completely agree

economic problem					
61.d Leprosy is not a problem	I Completely disagree	II disagree	III No response	IV agree	V Completely agree

62. What ways would be aware people about leprosy

a)

b)

63. Category (To be decided by the interviewer based on the assessment)

a) No deformity and no social and economic problems
b) With deformity but no social and economic problems
c) No deformity but with social and economic problems
d) With deformity but initial stage of social and economic dislocation
e) With deformity and with social and economic problems
f) With deformity already reached the stage of destitution

64. Any feedback, suggestions

APPENDIX II

Name list of clients supported by PFR (2000-2004)

S.N.	Name	Types of assistance	Budget	Remarks
1*	Bhim Bahadur Bhatta	Goat	8500	Gr #
2*	Dhan Bahadur B.K.	Buffalo	16000	Gr #
3*	Junga Bahadur Baram	Buffalo	20000	Gr#
4	Bijuli Pariyar	Tailoring Business	5000	Gr
5*	Sitaram Pariyar	Tailoring Business	9000	Gr#
6*	Lekh Bahadur Thapa	Carpenter business	35000	Gr#
7	Khadka Bahadur Gole	CMA	52000	Gr
8	Jas Bahadur Chetri	Buffalo shed	7550	Bg
9*	Ram Bahadur Sarki	Photograph	40700	Bg#
10*	Man Bahadur Thapa	CMA	50200	Bg (J)
11	Suku Nepali	House	15700	Bg
12*	Yam Bahadur Pun	Fruit nursery	10000	Bg (A)
13*	Ganesh Sharma	Toilet	8425	Bg #
14	Hom Bahadur Godar	Goat	10300	Tn
15*	Hem Bahadur Thapa	Goat	10000	Tn#
16*	Laxman B.K.	House	24550	Tn (A)
17	Dev Singh Thapa	House	25500	Tn
18*	Laxmi B.K.	Tailoring business	30000	Tn (A)
19	Chitra Bdr. Thakuri	Goats, loan, bee hives	15000	Tn
20*	Aita Bahadur B.K.	Buffalo	8500	Tn (M)
21*	Kopila Kumal	Fruit & veg. business	3000	Tn (M)
22	Min Bahadur Gurung	House & goat	21000	Tn
23	Durga Bahadur Nepali	Buffalo	9000	Tn
24*	Bishnu Maya B.K.	House & goat	44500	Tn#
25	Bishnu G.C.	House & goat	42480	Pr
26	Yam Malla	Goat	10000	Pr
27	Jhanka Raj Pande	House	17800	Pr
28*	Danda Raj Poudel	Medical shop business	10000	Pr#

29*	Kalpana Kunwar	ANM	13000	Pr#
30*	Rita B.K.	Tailoring business	52600	Pr#
31	Khum Bdr. Chpagain	Provision shop	16500	Pr
32*	Laxmi Bhusal	House	8500	Pr#
33*	Khil Bahadur Darjee	House & Chicken	17700	Pr#
34	Chandra K. Pariyar	Tailoring Business	11500	Pr
35	Icha Purna Adhikari	Goat	9500	Lm
36*	Jaya Prasad Gurung	House & goat	47000	Lm (M)
37*	Ganesh Gauli	House & goat	57000	Lm#
38*	Surya Kumari Bisural	House	11000	Lm#
39	Nanimaya Nepali	House	56500	Lm
40	Phulmati Sarki	House	9000	Ks
41	Bhim Bahadur Thakuri	House & goat	7000	Ks
42	Kabiram B.K.	Provision shop	15000	Ks
43	Bal Kumari Pariyar	Tailoring business	4000	Ks
44*	Kausila Sunar	House	2000	Ks#
45*	Santa Bahadur B.K.	Goat	5000	Ks#
46	Kumati Magar	House	5800	Ks
47	Ram Bahadur B.K.	Goat	10000	Ks
48	Fulmaya Chetri	Butcher shop	8500	Ks
49	Chandra Bdr. Chetri	Buffalo	18000	Ks
50	Badri Narayan Subedi	Hotel business	19000	Ks
51*	Thaman Singh Gurung	Goat	9000	Ks#
52*	Budhi Bahadur Karki	House & goat	50000	Ks (D)
53	Min Bahadur B.K.	Vegetable & fruit shop	2200	Ks
54*	Yam Kala Rana	House & bedding	13000	Ks (M)
55*	Mohan Thapa	House	11250	Ks#
56	Chandra Magar	Water pipe line	5750	Ks
57	Bishnu Maya Saru	Water pipe line	5750	Ks
58*	Tulsi Magar	Water pipe line	5750	Ks (A)
59	Keshar Bahadur Kami	Water pipe line	5750	Ks
60	Jhaman Singh Thapa	Water pipe line	5750	Ks

61*	Budhi Bahadur Pariyar	Water pipe line	5750	Ks#
62*	Chandra Bdr. Gurung	Water pipe line	5750	Ks#
63	Dil Bahadur Kami	Water pipe line	5750	Ks
64	Krishana Pd. Ghimire	Water pipe line	5750	Ks
65*	Chandra Bdr. Chetri	Water pipe line	5750	Ks#
66*	Jasmati Thapa	Water pipe line	5750	Ks#
67*	Singh B.K.	Water pipe line	5750	Ks (A)
68	Dil Bahadur Gharti	Water pipe line	5750	Ks
69*	Dal Bahadur Pariyar	Water pipe line	5750	Ks#
70*	Khar Singh Gurung	Water pipe line	5750	Ks#
71	Harka Bdr. Gurung	Water pipe line	5750	Ks
72	Devi Prasad Adhikari	Water pipe line	5750	Ks
73*	Somlal Sunar	Pig	12900	Ks (M)
74	Man Bahadur Sunar	Jewelry business	60000	Ks
75*	Utisuwa Damini	House	3000	Ks#
76	Juthi Pariyar	House	21000	Ks
77	Nawaraj Kharel	House	12000	Ks
78	Tika Ram Darjee	House & Goat	27000	Ks
79*	Iccha Bahadur B.K.	House	6000	Ks#
80	Dhurba Lal Poudel	House & ox	26000	Ks
81	Parbati B.K.	House	40000	Ks
82	Tham Bdr. Gurung	House & goat	28000	Sy
83*	Khadka Bdr. Gaha	House	12200	Sy#
84*	Dev Bahadur Magar	House	5000	Sy#
85	Shri Prasad Thapa	House & goat	42480	Sy
86*	Dhan Bahadur Magar	Pig	13500	Sy#
87	Amarsingh Gurung	Provision shop	16500	Sy
88	Dev Bahadur Magar	House	3000	Sy
89*	Khim Kumari Thakuri	Chicken	2000	Sy#
90	Lal Bahadur Darjee	Vegetable & fruit shop	2900	Sy
91	Lal Bahadur Damai	Tailoring Business	9500	Sy
92*	Top Bahadur B.K	Goat	4000	Sy#

93*	Putali Pokhrel	Provision shop	15000	Ar#
94*	Nom Bahadur Pun	Tea shop	8000	Ar#
95*	Durga Bahadur Sunar	Goat business	6500	Ar#
96	Jit Bahadur Kumal	Goat business	10000	Gu
97*	Rupa Basyal	Buffalo	20000	Pl#
98*	Devilal Neupane	House	19000	Pl#
99*	Bishnu Devkota	Buffalo	20000	Ch#
100*	Rajani Poudel	Tailoring business	14800	Ch#
101	Parse Magar	House & pig, ox	10000	Ch
102*	Krishna Kumal	House & pig	103600	Ch#
103*	Prem Prasad Bastola	Vegetable & fruit shop	12000	Ch (M)
104*	Basanti Ranabhat	Tailoring training	25750	Ch#
105	Jeevan Darai	House	8000	Ch
106	Jeet Bahadur Moktan	House & chicken	17000	Ch
107	Dhaka Bahadur Kumal	Tailoring business	8300	Np
108	Ganga Ram B.K.	House & goat	1500	Np
109	Raj Kumari G.C.	Tailoring business	33740	Np
110*	Prasad Gurung	House	29800	Np#
111	Jokhe Ale Magar	Pig	9000	Np
112	Til Bahadur Bote	Carpentry business	6000	Np
113*	Bhakata Bahadur B.K.	House & goat	14500	Np#
114*	Srimaya Saru	House	45000	Np#
115	Nathu Patel	Pan (beetle) shop	8000	Np
116	Ram Bahadur B.K.	Goat	3000	Np
117*	Jhinku Harijan	House	32000	Np#
118	Yam Bahadur Gurung	House	17000	Np
119	Prem Narayan Mahato	House	15500	Np
120*	Soroti Ahir	Buffalo	18000	Np#
121	Budhiman Thapa	Goat	10000	Np
122*	Narayan Pd. Mahato	House	22000	Np#
123*	Mahal Bdr. Chaudhary	Tailoring business	46600	Np (M)
124*	Shivalal Subedi	Goat	10000	Np (D)

125*	Jange Pariyar	House & goat	60966	Np#
126	Basu+Setu Tamang	House	58466	Np
127	Balaram Pun	House & goat	60966	Np
128	Jeevraj Mahato	CMA	15000	Np
129*	Govinda Ahir	Buffalo	23000	Np#
130	Top Bdr. K.C.	Radio/TV repair shop	16900	Np
131	Govinda Ahir	Buffalo	23000	Np
132	Juna Nepali	House	11650	Rp
133	Ramu Chaudhari	Vegetable & fruit shop	10000	Rp
134	Sanu Thapa	House	40000	Rp
135	Man Kumari Nepali	Pig	12000	Rp
136	Raju Lohar	Carpentry business	8000	Rp
137	Rita B.K.	Tailoring business	20000	Rp
138*	Tika Ram B.K.	House	15000	Rp (M)
139*	Prem Kala B.K.	Weaving business	5000	**Rp#**
140*	Nandakali Darjee	Ox	13500	Rp (A)
141	Gopal Dargee	House	25000	Rp
142*	Suryaman Chaudhari	House	18000	Rp#
143*	Jug Bahadur Magar	Provision shop	12000	Rp#
144	Sita Ram Chaudhary	Vegetable shop	2500	Rp
145	Baburam B.K.	House	46000	Rp
146	Nar Bahadur B.K.	House	21500	Rp
147	Ram Samaj Dhobi	Vegetable shop	7000	Rp
148*	Jit Bahadur Rana A	House	5000	Rp (M)
149	Debu Thapa	Provision shop	16000	Rp
150*	Dev Bahadur Sunar	Vegetable & fruit shop	3000	Rp#
151*	Toplal Thapa	Khaja shop	14500	Rp#
152*	Sadhana Chadhary	Tailoring business	26570	Kp#
153*	Shanti Devi Dhawal	House & veg. shop	13500	Kp (A)
154*	Deepu Khadka	Fruit shop	15000	Kp#
155*	Ram Urga Chammar	Bicycle repair shop	6000	Kp (A)

		Total	2738593	

* The star indicates the sampled respondents of the study.

The interview was taken with the respondents.

(A) During home visit, the respondents were not in home (Absent).

(D) The “D” denotes the respondent was died.

(M) The respondents were migrated (M) in different places for work.