YANGON UNVERSITY OF ECONOMICS

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A STUDY ON SOCIO-ECONOMIC CONDITIONS OF LEPROSY AFECTED PEOPLE IN NAUNG KAN VILLAGE, EASTERN SHAN STATE

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EMDevS-27 (15th BATCH)

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A STUDY ON SOCIO-ECONOMIC CONDITIONS OF LEPROSY AFECTED PEOPLE IN NAUNG KAN VILLAGE, EASTERN SHAN STATE

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Development Studies (EMDevS).

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ABSTRACT

Leprosy is a chronic infectiours disease and only in Myanmar, around 3,000 new patients are recorded every year by Myanmar Christian Leprosy Mission. This study focuses on the Socio-Economic conditions of Leprosy effected people in Naung Kan, Keng Tung Township, Eastern Shan State and present the accessibility to healthcare services, education, vocational trainings, employment opportunities, discrimination and participation in society. This study used descriptive analysis based on primary data collected by interviewing with structured questionnaires, and secondary. The study found out that Leprosy people in Naung Kan village have got regular treatment; health care and education service. The minority are taken care by Christian Missionary, Government and Non-Government with livelihood trainng, grants and infrastructure support. Moreover, they have limited awareness on leprosy and are discriminated from the society. In addition, there is insufficient support to leprosy people people for rehabilitation and medical treatment. Therefore, this study suggests the importance of health care service and advocacy, vocational training, and livelihood support to be accessible by the leprosy people.

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

ABM	Amercian Baptist Missions
BHS	Basic Health Staf
CBR	Community-based rehabilitation
CDRs	Case Detection Rate
ECCD	Early Child Care Development
FOC	Free of Charges
G2D	Grade 2 Disability
HE	Health Educaion
INGO	International Non-Government Organization
LAC	Leprosy Awareness Campaign
MB	Multibacillary
MDT	Multidrug therapy
MDT	Multidrug Therapy
NCDR	New Case Detection Rate
NGO	Non-Government Organization
PALS	Person Affected by Leprosy
PB	Paucibacillary
POD	Prevention of Disability
QOL	Quality of Life
RFT	Released from Treatment
SALT	Sloping Agricultural Land Technology
SES	Socioeconomic Status
TAG	Technical Advisor Group
UN	United Nations
WHO	World Health Organization

CHAPTER I
INTRODUCTION

1.1 Rationale for the Study

Leprosy is a chronic infectious disease caused by Mycobacterium leprae. It is highly infectious, but its morbidity is low because a large portion of the population is naturally resistant to this disease. Leprosy affects mainly the skin and peripheral nerves. Its diagnosis is established based on skin and neurologic examination of the patient. Early diagnosis is very important. The timely and proper implementation of treatment will prevent sequelae and physical disabilities that have an impact on the individual's social and working life, which are also responsible for the stigma and prejudice regarding this disease (An Bras Dermatol., 2104,Mar-Apr).

The ministry of Health and Sports to conduct applied surveys on the reason is why the patients fail to take medicine and 0.39 in 1,000 populations suffered from leprosy according to the 2018 figures. The ministry extended its work to find new leprosy patients in wards and villages as around 2,000 new patients are detected every year (Eleven, 2019,October,3).

Leprosy is a chronic disease that there were two hundred sixteen thousand one hundred and eight (216,108) new leprosy cases registered globally in 2016, according to official figures from 145 countries from WHO. 2014 Census shows that Myanmar has two million three hundred eleventh thousand two hundred and fifty (2,311,250) persons, or 4.6% of its population, living with some form of disability. Two thousand six hundred (2,600) to three thousand (3,000) new patients are recorded every year according by Myanmar Christian Leprosy Mission (MCLM), 2017.

The elimination target is different from the eradication target. Myanmar is not in the eradication stage. The word is used by the state and public differently. At national level, it is below 10,000patients but in the state and region level, it has not reached the target. So, 2,600 to 3,000 new leprosy patients are found every year.

After such declaration, international assistance in leprosy has declined and it has affected the anti leprosy department under the Ministry of Health. “Once the announcement that elimination target had been reached was made, international support declined. It affected the anti-leprosy department. As they have no fund, they have to try very hard to give treatment to existing patients let alone finding new patients”. Some patients have to wait to obtain their medicines as they have not been listed with the department and “When no immediate treatment is obtained, some get deformities If severe, it is difficult to give treatment and they can no longer lead a sociable life”. However, it is easy to get medicines in state-controlled areas, “it is difficult to get medicines in areas controlled by armed groups. The patients don’t want to disclose the fact that they have contracted the disease. Only when they can no longer hide, they come to hospital for treatment. Among the patients, children and students are also included”. “A leprosy patient can spread the disease to family members as well as others. After contracting, it takes five to 10 years for the disease symptoms to appear,” (Soe, 2017).

The state has the responsibility to take care of mothers and children, orphans, children of deceased military personnel, elderly people and persons with disabilities’ which was approved on 28th May 2008 by Section 32(A) of the Constitution of the Union of Myanmar. States People with disabilities in Myanmar face many barriers to participating in society and specifically in meaningful economic activity. It’s important to provide the opportunity to achieve their full potential within both society and the economy. (Myanmar, 2008) They face physical, attitudinal, communication, and institutional barriers that exacerbate their exclusion. Moreover, preventing people with disabilities from living a full life and contributing meaningfully to their communities, this exclusion deprives

Myanmar of the significant economic activity that their participation could contribute to the country. People affected by leprosy and disability should overcome barriers such as delayed access to health services, lack of access to private and public spaces, and the ignorance and discrimination that prevent their full participation and acceptance in society. People with disabilities also face discrimination and do not receive adequate protection under the Myanmar law. Stigma and discrimination, as well as the non-readiness of the health system, hamper their access to health care and education (Global Justice Centre and Gender Equity in Myamar, 2016).

Leprosy affected people have lost of their place in the world after contracting leprosy. Sadness, frustration, loss of confidence, devaluation of their own capacity, stress and hopelessness were some of the emotions described due to leprosy. All of those physical impacts challenged their life and also influenced their social and economic situation. Several people affected became reserved, shy and ashamed ad isolated themselves, but at the same time, several family members and people in the community also isolated people affected. They were rejected when the leprosy started. Moreover, issues as loneliness, dependence on others, other health issues and often an alarming financial situation. Leprosy is one of the world's oldest and most stigmatized disease. In Myanmar, people who suffered leprosy had loss of confidence, deflation of their own capability, stress and hopelessness. Naung Kan Village is one of the well-known leprosy colonial places in Myanmar and people who affected leprosy are facing difficulties to make social networks, low job opportunities and hard to access education. Therefore, this study is focused to observe the socio-economic situation of leprosy affected people who lived in Naung Kan Village of Myanmar.

1.2 Objectives of the Study

The objectives of the study aim

- to examine socio-economic conditions of Leprosy affected people and
- to explore the employment opportunities accessible by Leprosy affected people

1.3 Method of Study

The descriptive method was used in this study and both Primary data and Secondary data will be collected through the qualitative (FGD) and quantitative methods. The qualitative data were applied in Naung Kan Village, Keng Tung Township. The primary data which is the individual survey of (123) households out of (123) households (which is 100% of the households) in Naung Kan village, Keng Tung Township and Focus Group Discussion were conducted with the local respondents from that villages. Both male and female from age 18 to 60 were interviewed and Random Sampling Method will be applied in Household level survey. The secondary data was collected from reports and publications from Ministry of Health, WHO, other CSOs and articles from newspaper, websites and

journals from 2008 to 2018. In addition, this study will also have face to face interviews with leprosy people, their family members, the Sister of Charity, the care givers, influencers, head-villager, government and non-governmental sector. The period of this study was from August 2018 to July 2019 (one year).

1.4 Scope and Limitations of the Study

This study focuses on Leprosy affected people in Naung Kan village, Mong Latt region in Keng Tung Township in Eastern Shan State, Myanmar. In Eastern Shan State, Keng Tung has three districts; Keng Tung, Tachileik and Mong Sat. Keng Tung District consists of five quarters, thirty one big village groups which has over three hundred villages. Naung Kan village is one of the Mong Latt village tract's eleven villages. At the Mong Latt village, there are one thousand one hundred and eighty-five (1,185) households with total population of six thousand eight hundred and forty-two (6,842). The Leprosy affected people stay in Naung Kan village, which is also called Catholic Mission Leprosy Colony which is established in 1923 (Sao In Ta Lieng/ Sawbwa in charge of the area).

1.5 Organization of the Study

The study is organized into five chapters. The chapter one is introduction composed of rationale of the study, objectives of the study, method of study, scope and limitation of the study and organization of the study. Chapter two is Leprosy and historical background, socio-economic status affects our society and impact of minorities, discrimination and marginalization. Chapter three is overview of Leprosy condition and implementation in Myanmar, historical background of Keng Tung Township, brief of Naung Kan Leprosy Colony and treatment of Leprosy. Chapter four is Survey analysis of study area and Chapter five is conclusion which consists of key findings of the study and suggestions.

CHAPTER II
LITERATURE REVIEW

2.1 Definition of Leprosy

Leprosy is a chronic infectious disease which affects the peripheral nerves and the skin. It is often referred to as 'the oldest disease known to man (SG, 1985) . The earliest written records describing leprosy come from India and date back to about 600 BC. The earliest remains of people confirmed to be affected with leprosy stem from Egyptian excavations which disclosed leprous skulls buried in the second century BC. (Meima, 2004) The bacilli do not survive in the environment for more than 9 days (mean temperature 36.7^{o} and humidity 77.6^{o}). For research purposes the bacilli are cultivated in the foot pads of immune compromised mice. Leprosy is a disease with social stigma. Social stigma has been defined as a physical, mental or social attribute of an individual or group that elicits an adverse or discriminatory response from others (Goffman E., 1963).

Leprosy is one of the most prevalent neuromuscular disorders caused by several strains of Mycobacterium leprae. The disease has recently shown reemergence due to development of resistant strains. The gravity of the problem is being underplayed due to lack of proper infrastructure for reporting of cases and the social stigma associated with the disease, which hinders self-reporting. Large numbers of new cases of leprosy come up every year despite WHO and state-run initiatives (WHO, International classification of impairment, disabilities and handicaps,Geneva, 1980). The situation made further grim by the presence of unofficial leper colonies resulting from boycott by the society. Multidrug therapy in children is not taken seriously resulting in deformities and secondary infections (Shukla, 2018)

Leprosy is an infectious disease predominantly of skin and peripheral nerves, caused by the obligate, intracellular, acid-fast bacillus Mycobacterium leprae. The organism shows tropism for macrophages and Schwann cells (Britton WJ, 2004).

The pathology and clinical phenotype of leprosy is determined by the host immune response to M. leprae. Patients develop leprosy on a clinical spectrum ranging from tuberculosis leprosy through borderline forms to lepromatous leprosy (LL) of the Ridley–Jopling classification (Ridley DS, 1966). Patients with tuberculoid leprosy have a strong cell mediated immune response to M. leprae limiting the disease to a few well-defined skin lesions and/or peripheral nerves (Turk JL, 1969). Patients with LL have absent cellular immunity and high titers of antibodies against M.leprae, which are not effective in controlling the bacilli (Moran CJ, Ryder G, Turk JL, 1972).

Leprosy is basically a skin disease and the most common signs and symptoms of leprosy are usually seen in the skin which appears as a single or multiple hypo-pigmented (white) or hyperpigmented (reddish) patch. In some cases, there can be reddish nodules or shiny diffuse thickening of the skin. In addition, the bacilli also attack the peripheral nerves and as a result of which the nerves are damaged and manifest clinically as thickened, hard and enlarged nerves. Because peripheral nerves are damaged, areas of the skin supplied by the damaged nerves lose the sensory function. The patient does not feel any pain in the areas of the skin lesion. In addition, the muscles supplied by the damaged nerve will also become weak and ultimately atrophy if not treated at an early stage. Sometimes, in patients with low resistance to M. leprae infection, the skin lesions appear as small reddish infiltrations or reddish nodules on the face, ear lobes, body and extremities[8]. Leprosy skin patches do not itch (Kyaw Lwin, Tin Myint, Maung Maung Gyi, 2015).

2.2 Historical Background of Leprosy

For thousands of years leprosy has struck fear into people the world over. It was well recognized in the oldest civilizations of China, Egypt and India and it is generally claimed the first clear and accurate description of leprosy was in India about 600 BC (Dave, 1987). The Leprosy records in Bergen, Norway, however, say that leprosy is mentioned in sources from Egypt from as early as 1350 BC (Nedrebø, 2001) . There are several references to leprosy and the word ‘lepers’ in the Bible with Leviticus, the third book of Moses, referring to the disease as a plague and giving rules on how to behave towards ‘lepers’. The New Testament showed Jesus demonstrating considerable mercy and special concern towards people with leprosy, whom other people hated.

It is well known and agreed that leprosy related disability is difficult to hide and therefore compounds the stigma associated with the disease, reinforcing social

exclusion and disempowerment. Added to this difficulty, there remains legislation relating to leprosy in some countries which directly disobeys the Universal Declaration of Human Rights (United Nations, 1948)

Leprosy was widespread during the 13th century in Europe (WHO, Elimination of Leprosy, 2005). Evidence of this is built into gothic churches in Europe and Britain; the so called 'leprosy squint holes' through which the person with leprosy would peer and watch the priest at the alter celebrating mass. Previous to this, a service of exclusion would have taken place, with the leprosy affected person covered under a black cloth and the mass of death read followed by a list of prohibitions: never again to enter a church, a house, a roadhouse or a marketplace; or to walk through narrow lanes or speak 'downwind' to anyone; Never to speak with children; Always to wear a 'leper's' uniform, which included gauntlet gloves, and a 'leper' warning given either with a 'leper's bell' or 'leper's rattle' when approaching other people. For all practical purposes the person with leprosy was 'dead' to society (Davey, 1987). By the 17th century, Norway and Iceland were the only countries in Western Europe that had big numbers of people with leprosy.

This disease has been known as leprosy since the biblical times, with reports of cases dating over 3000 years ago. There are doubts whether leprosy originated in Asia or Africa. The term Leprosy is a tribute to the Norwegian physician Gerhard Armauer Hansen, who identified the bacillus *Mycobacterium leprae* as the cause of the disease in 1873. In the past 10 years, between 2009 and 2018, by WHO region. The trend shows a slow decrease in the 34 in the Americas Region (AMR), 17 in the Eastern Mediterranean Region (EMR), 23 in the European Region (EUR), 11 in the South-East Asia Region (SEAR) and 33 in the Western Pacific Region (WPR). The reporting year was the 2018 calendar year for most countries, although some reported on a different 12-month period (e.g. in India, data). The data for previous years was updated with new information received from Member States.

(i) Case detection in WHO Regions: WHO's South East Asia Region reported 71% of all global cases: 2 countries – India (120, 334 cases) and Indonesia (17,017 cases) contributed 92% of the cases in this Region. In WHO's Region of the Americas, Brazil continued to report high case levels (28,660 cases) representing 93% of all cases in this Region. Combined, Brazil, India and Indonesia accounted for 79.6% of all the new cases detected globally. Of the 159 countries and territories that provided data, 32 reported 0 cases, 47 reported 1–10 cases, 24 reported 11–100 cases,

41 reported 101–1,000 cases and 15 reported more than 1,000 cases, including Brazil, India and Indonesia which each reported more than 10,000 new cases. Data from the national leprosy programmes of 23 priority countries (Angola, Bangladesh, Brazil, Comoros, Côte d'Ivoire, Democratic Republic of the Congo, Egypt, Ethiopia, Micronesia (Federated States of), India, Indonesia, Kiribati, Madagascar, Mozambique, Myanmar, Nepal, Nigeria, Philippines, South Sudan, Sri Lanka, Somalia, Sudan and United Republic of Tanzania) accounted for 199,400 of new cases, representing 96% of total cases worldwide. This number compares favorably with cases reported in 2017; however, due to improved active case detection, more new cases were detected in Brazil, Indonesia and Somalia. (WHO, 2019)

(ii) Case detection in children: Detection of leprosy cases in children is considered an indicator of recent transmission of infection in the community. In 2018, reports on pediatric cases with grade 2 disabilities (G2D) were received from only 139 countries, although all national programmes were urged to document disability status for all patients, including children. In 2018, WHO's South East Asia Region accounted for 74% of all new pediatric cases globally, whereas the African Region reported 1723 cases, which was slightly higher than in the previous year (1684). The pediatric cases detected in global priority countries accounted for 96% of new pediatric cases, showing a similar proportion as total new cases. (WHO, 2019).

2.3 Socio Economic Status (SES) and Influence on Minorities

Socio economic status has been defined as the position that an individual or family occupies with reference to the prevailing average standards of cultural and material possessions, income, and participation in group activity of the community. It is determined basis of the education, occupation and income level. Socio-economic development is the process of social and economic development in society. Socio-economic development is measured with indicators, such as GDP, life expectancy, literacy and levels of employment. Socioeconomic status (SES) encompasses not just income but also educational attainment, financial security, and subjective perceptions of social status and social class. Socioeconomic status can encompass quality of life attributes as well as the opportunities and privileges afforded to people within society. Poverty, specifically, is not a single factor but rather is characterized by multiple physical and psychosocial stressors. Additional, SES is a regular and consistent predictor of a vast array of outcomes across the life span, including physical and

psychological health. Thus, SES is relevant to all realms of behavioral and social science, including research, practice, education and advocacy.

SES affects overall human functioning, including our physical and mental health. Low SES and its correlates, such as lower educational achievement, poverty and poor health, ultimately affect our society. Inequities in health distribution, resource distribution, and quality of life are increasing in the United States and globally. Society benefits from an increased focus on the foundations of socioeconomic inequities and efforts to reduce the deep gaps in socioeconomic status in the United States and abroad.

The relationship between SES, race and ethnicity is intimately intertwined. Research has shown that race and ethnicity in terms of stratification often determine a person's socioeconomic status (U.S. Census Bureau, 2009). Furthermore, communities are often segregated by SES, race, and ethnicity. These communities commonly share characteristics: low economic development; poor health conditions; and low levels of educational attainment; Low SES has consistently been implicated as a risk factor for many of these problems that plague communities. Research indicates that there are large health disparities based on social status that are pervasive and persistent. These health disparities reflect the inequalities that exist in our society. It is important to understand how various social statuses intersect, because race and socioeconomic status affect health exclusively as well as mutually (Williams & Mohammed, 2013).

2.3.1 Discrimination and Marginalization

Discrimination and marginalization can serve as a limitation to upward movement for ethnic and national minorities seeking to escape poverty. In the United States, 39 percent of African-American children and adolescents and 33 percent of Latino children and adolescents are living in poverty, which is more than double the 14 percent poverty rate for non-Latino, White, and Asian children and adolescents (Kids Count Data Center, Children in Poverty 2014). Minority racial groups are more likely to experience multidimensional poverty than their White counterparts (Reeves, Rodrigue, & Kneebone, 2016). American Indian/Alaska Native, Hispanic, Pacific Islander and Native Hawaiian families are more likely than Caucasian and Asian families to live in poverty (U.S. Census Bureau, 2014). Although the income of Asian American families often falls markedly above other minorities, these families often

have four to five family members working (Le, 2008). African-Americans (53 percent) and Latinos (43 percent) are more likely to receive high-cost mortgages than Caucasians (18 percent; Logan, 2008). African American unemployment rates are typically double that of Caucasian Americans. African-American men working full-time earn only 72 percent of the average earnings of comparable Caucasian men and 85 percent of the earnings of Caucasian women (Rodgers, 2008).

2.3.2 Education

Despite affected changes, large gaps remain when minority education attainment and outcomes are compared to white Americans. African-Americans and Latinos are more likely to attend high-poverty schools than Asian-Americans and Caucasians (National Center for Education Statistics, 2007). From 2000 to 2013 the dropout rate between racial groups narrowed significantly. However, high school dropout rates among Latinos remain the highest, followed by African-Americans and then Whites (National Center for Education Statistics, 2015). In addition to socioeconomic realities that may deprive students of valuable resources, high-achieving African American students may be exposed to less rigorous curriculums, attend schools with fewer resources, and have teachers who expect less of them academically than they expect of similarly situated Caucasian students (Azzam, 2008). 12.4 percent of African-American college graduates between the ages of 22 and 27 were unemployed in 2013, which is more than double the rate of unemployment among all college graduates in the same age range (5.6 percent; J. Jones & Schmitt, 2014).

2.3.3 Health

Institutional discrimination creates barriers to health care access. Even when stigmatized groups can access care, cultural racism reduces the quality of care they receive (Williams & Mohammed, 2013). Racial and ethnic minorities have worse overall health than that of White Americans. Health disparities may stem from economic determinants, education, geography and neighborhood, environment, lower quality care, inadequate access to care, inability to navigate the system, provider ignorance or bias, and stress (Bahls, 2011). Socioeconomic status and race/ethnicity have been associated with avoidable procedures, avoidable hospitalizations, and untreated disease (Fiscella, Franks, Gold, & Clancy, 2008). At each level of income or

education, African-Americans have worse outcomes than Whites. This could be due to adverse health effects of more concentrated disadvantage or a range of experiences related to racial bias (Braveman, Cubbin, Egerter, Williams, & Pamuk, 2010). Low birth weight, which is related to a number of negative child health outcomes, has been associated with lower SES and ethnic/minority status (Fiscella et al., 2008). There are substantial racial differences in insurance coverage. In the preretirement years, Hispanics and American Indians are much less likely than Whites, African-Americans, and Asians to have any health insurance (Williams, Mohammed, Leavell, & Collins, 2010). Socioeconomic deprivation and racial discrimination have been implicated in higher psychological distress. Wealth partially explains racial and ethnic differences in depression. Negative net worth, zero net worth and not owning a home in young adulthood are significantly associated with depressive symptoms, independent of the other socioeconomic indicators (Mossakowski, 2008). Hispanics and African-Americans report a lower risk of having a psychiatric disorder compared with their white counterparts, but those who become ill tend to have more persistent disorders (McGuire & Miranda, 2008). Research on post-traumatic stress disorder (PTSD) indicates that African-Americans, Hispanics, Asians, American Indians, and Native Hawaiians have higher rates of PTSD than Whites, which are not accounted for by SES and their history of psychiatric disorders (Carter, 2007). American Indians are at heightened risk for PTSD and alcohol dependence (McGuire & Miranda, 2008). Perceived discrimination has been shown to contribute to mental health disorders among racial/ethnic groups such as Asian Americans and African Americans (Jang, Chiriboga, Kim, & Rhew, 2010; Mezuk et al., 2010).

2.3.4 Livelihood

Livelihood is the sum of ways and means by which individuals, household's and/ or communities make and sustain a living. It is a concept that encompasses practices and processes much beyond the regular income generating activities. By and large, livelihood encompasses not only the economic activities that people engage in, but also their social, institutional and organizational environment. Participation in an economic activity is necessary for every human being, not only for sustenance, basic survival or supplementing the family income, but also to contribute to one's self esteem and enhancing self-fulfillment. 'Livelihood comprises the capabilities, assets (including both material and social resources) and activities required for a means of

living. A livelihood is sustainable when it can cope with and recover from stress and shocks and maintain or enhance its capabilities and assets both now and in the future, while not undermining the natural resource base. Livelihood is a system that depends on the assets people draw upon, the strategies they develop to make a living, the context within which it is developed and finally all those factors that make a livelihood more or less vulnerable to shocks and stresses. The livelihood assets required may be tangible or intangible. These could also be categorized into groups such as human capital (skills, knowledge, health and ability to work), social capital (including informal networks, membership of formalized groups and relationships of trust that facilitate co-operation and economic opportunities), natural capital (land, soil, water, forests and fisheries), physical capital (basic infrastructure, such as roads, water & sanitation, schools, ICT; and producer goods, including tools, livestock and equipment), financial capital (financial resources including savings, credit, and income from employment, trade and remittances), and political capital (access to citizenship, right to vote, to participate in political affairs, legal rights)The complex interplay of institutions, processes and policies, such as markets, social norms, and asset ownership policies affect one's ability to access and use assets for a favorable outcome. As the contexts change they create new livelihood obstacles or opportunities. The access and use of these assets, within the aforementioned social, economic, political and environmental contexts, form a livelihood strategy. One important characteristic of livelihoods is their interdependence. Very few livelihoods exist in isolation. A given livelihood may rely on other livelihoods to access and exchange assets. Thus, positive and negative impacts on any given livelihood will, in turn, impact others (UNDP, 2012).

2.4 World Health Organization Standards of Leprosy Treatment

The M.Leprae is known as tuberculosis leprosy and first seen as pigmented patches on the skin usually attended by loss of feeling. Additional symptoms become evident as M.leprae attacks surface nerves in cool parts of the body, and areas such as hands and feet gradually experience loss of feeling also. Later injuries occur because of lack of pain and often go unseen for some time with permanent deformity and disability resulting. Left untreated, leprosy will continue to destroy nerves causing anesthesia, and once lost, feeling will never return, meaning prevention of disability becomes a lifelong battle. A worse form of the disease is lepromatous leprosy which

is very infectious. Here M.leprae multiplies at a steady rate and infiltrates the skin producing unsightly nodules on the face and body.

From the early 1900s to the late 1940s, leprosy was treated by giving injections of oil from the chaulmoogra nut. While this appeared to work for some people, longterm benefits were questionable. Dapsone pills were used during the 1950s but disappointment followed when M.leprae began developing Dapsone resistance (Davey, 1987: 61). Drug trials on the island of Malta in the 1970s led to an effective combination of drugs and in 1981 the World Health Organisation recommended Multi Drug Therapy (MDT). The combination of Rifampicin and Dapsone (known as paucibacillary multidrug therapy or PBMDT) over six months or the triple drug combination of Rifampicin, Dapsone and Clofazimine (known as multibacillary multidrug therapy or MBMDT) over twelve months were highly effective in curing leprosy (Lockwood, 2005: 230). This cure was a major discovery.

2.5 Review on Previous Studies

Many case stories on leprosy, among them studies of the review on leprosy affected people in Indonesia, Japan and Myanmar. The Myanmar Health Sciences Research (2008) in the study of "Lights and shadows of people affected with leprosy in Sittaung Area, Myanmar" the research analysis focused on how the PALs told their stories about their social lives in their community. Study population was PALs aged 18 years and above residing in Sittaung Area. The emphasis was on studying PALs from social group difference perspectives. A total of 38 PALs were included in the study. Among PALs of lower social group, economic difficulties were their concerns more than social problems emanating from their disability. The study highlighted that improvement in the economic status of PAL could bring the person out of shadow. It was also found that allowing PALs, especially of lower social group, participate in local social organizations by the community would discard away their feelings of being in shadows. Resilient spirit of each individual PAL was found as the key factor that could pull a PAL out of shadow. It is recommended that, especially for PALs of low social group, empowerment education approach complimented with socio-economic strategies could bring their lives out of shadows (The Myanmar Health Sciences Research, 2008).

Majumder N (2015) in her thesis of "Socio-economic and health status of leprosy affected person: A study in Jharkhand" the results of the research indicated

that the respondent's low level of awareness about the disease, resulting in delayed treatment. 14/25 (56%) percent of female and 13/25 (52%) of male respondents are considered untouchable by their natal families, thus forced to stay in congested leprosy colonies resulting in other social and health related issues. It was observed that leprosy cured children and also children of LAP are being denied admission in any school, due to the social stigma attached to it. 27/50 (54%)of leprosy patients and leprosy cured people (mostly with visible deformities) were found to practice begging as their sole means of livelihood. Many LAPs are also engaged in cultivation and small-scale business particularly among the rural population. An amount of gender disparity was also observed in the employment pattern among the LAPs. Among the respondents 15/25 (60%) of the females are beggars as compared to 12/25 (48%) of the male respondents, 5/25 (25%) of males are each engaged in cultivation and small-scale businesses in comparison to 1/25 (4%) of female and 6/25 (24%) of the female respondents are unemployed as compared to 2/25 (8%) of male respondents. It was observed that only 30% of the respondents were satisfied with the government treatment, 26% partially satisfied and rest were not satisfied with the government leprosy care system. Most of them wanted to seek treatment from the private health care providers. Overall this study reflects the poor socio-economic conditions of the LAPs. Though results of this exploratory study cannot be extrapolated to country or region or state without studying the situation in detail, it highlights the need for more in-depth studies and of government intervention in the form of encouraging awareness activities in the communities, engaging NGOs in case detection and after care service provision and rehabilitation of the LAPs (Majumder, 2015).

Bipin Adhikari & Sujan Babu Marahatta (2014) in the article “Risk factors of stigma related to leprosy – A Systematic Review” that, the studies indicated that leprosy stigma is still a global phenomenon, occurring in both endemic and non-endemic countries. The consequences of stigma can range from the psychosocial dysfunction to isolation, rejection and participation restriction. Despite the variation in prevalence of different types of stigma, its severity and nature, the risk factors associated with stigma are remarkably similar. They include visible impairments, disability, low socioeconomic status, low education and the various perceptions regarding leprosy. This suggests that risk factors contributing to the development of stigma are perhaps of a similar nature thus indicating that management of stigma in diverse culture is possible by implementing related stigma-reduction strategies to

counteract the various risk factors in various settings. Nonetheless, establishing the particular risk factors that contribute to stigma in different settings can future aid the design of specific interventional programs to address the different determinants followed by the evaluation and monitoring of the stigma interventions at different levels and settings (Bipin Adhikari & Sujan Babu Marahatta, 2014).

CHAPTER III
BACKGROUND HISTORY OF THE KENG TUNG TOWNSHIP

3.1 Background History of Leprosy in Myanmar

Before the Second World War, the Burma Branch of the British Empire Leprosy Relief Association (now known as LEPRA Health in Action) provided a grant to establish District Leprosy Associations. With that grant, leprosy colonies were built by the respective associations in 9 Districts. In addition, 2 leprosy colonies were also run by the Shan State Government in Lashio and Maing Tauk Village in Inlay area.

With the launching of the Leprosy Control Programme in the early fifties after the country's independence, in addition to the 11 existing colonies 5 more colonies were established making it a total of 16 colonies throughout the country to accommodate leprosy patients with severe disabilities and for those who faced severe economic and social problems due to discrimination. Admission into these colonies was not compulsory. These colonies were administered under the District Leprosy Relief Association. The District Leprosy Relief Association was registered as a charitable association and headed by the Deputy Commissioner of the District. Members of this association had to pay a subscription of 5 Kyats annually. Each colony accommodated around 50 to 100 patients.

At the central level, the Union of Burma Leprosy Relief Association was established which was the successor to the British Empire Leprosy Relief Association. The President of the Union of Burma was the patron and the Minister of Health was the chairperson. The Director of Health Services and the Assistant Director of Leprosy acted as secretaries along with the Manager of the State Bank of India acting as treasurer and took care of accounts. After independence, another association called the British Empire Leprosy and Tuberculosis Association was closed and some funds from this association were transferred into the Union of Burma Leprosy Relief Association. This Association supported the District Leprosy Relief Associations with funds to help run the leprosy colonies.

Both these associations worked closely with the National Leprosy Control Programme and provided funds to help establish offices or new leprosy control teams in the districts. By 1963, there were 3,681 people affected by leprosy living in these colonies amounting to 1.5% of the total case load in the country. Patients were provided living accommodations and a monthly allowance of 20 Kyats for food, half of which was provided by the District Council and the other half from the central government budget. All patients admitted to these colonies received treatment with dapsone.

However, in 1963 all associations and organizations in the country were dismantled by the Revolutionary Council of the Union of Burma and under this order both the Union of Burma Leprosy Relief Association and the District Leprosy Relief Associations ceased to exit. The funds remaining in the Union of Burma Leprosy Relief Association were donated for building and renovating living quarters for patients in leprosy colonies, building out-patient departments for leprosy patients in district hospitals, and provided the district leprosy control teams with stationery, office equipment and furniture.

However, as the National Leprosy Control Programme expanded its coverage more and more cases came forward to be admitted into these colonies. There came a time when new cases could not be accepted anymore as living accommodations and funds became insufficient By mid-sixties new admissions into these colonies were stopped. As dapsone treatment was provided as a domiciliary treatment to patients it became apparent that there was no need to treat them in institutions. However, patients affected by leprosy came on their own will to live in and around these colonies and sometimes they brought along their families because of severe stigma and discrimination directed towards them in the community.

The biggest draw-back in treating patients in colonies and homes in Myanmar was that these patients over a period of time became more outcasts and stigmatized by the general community and re-integration into the society became almost impossible. As the allowance provided by the government for food became insufficient due to high inflation, people affected by leprosy living in these colonies practically had to fend for themselves for their daily existence. With rapid urbanization occurring during the last 2 decades especially in district towns, encroachments by new settlements occurred and these government operated leprosy colonies slowly lost their identity and merged unofficially into the peri-urban areas where first and second

generation off-springs of leprosy affected persons and the general population co-exist without any social problems. Over the years some of these colonies totally integrated into the peri-urban areas of nearby towns and no longer exist as specific leprosy colony anymore.

In addition to the above-mentioned leprosy colonies, a new resettlement village called Mayan Chaung was established in 1989 - 1990 that was located about 30 miles outside Yangon City by the government. The residents of this colony are mainly people affected by leprosy who at one time lived around the Htauk Kyant Leprosy Hospital. This establishment is currently supported by financial assistance from local well-wishers and Ministry of Social Welfare. Recently, Mother's Trading and Construction Company Limited built new living quarters for persons affected by leprosy and named it Myitta Parahita Gayhar. This donor also provides funds for daily meals as part of its cooperate social responsibility activities. This leprosy home accepts new admissions and currently accommodates around 100 persons affected by leprosy.

In addition to the government operated colonies, there are 4 colonies still functioning in the country located in Keng Tong, Loilem, Thayet and Mawlamyaing Towns which are run by missionaries. The Naung Kan Leprosy Home in Keng Tong, Eastern Shan State was established in 1934 as a village and it later transformed into a home for leprosy affected persons. The colony in Loilem which is run by the Roman Catholic Mission was established in 1926 as a shelter to isolate leprosy affected persons. It now functions as a home and renders medical services in collaboration with the district leprosy control team. It also provides social and economic rehabilitation services and carries out health education activities in local ethnic languages. The one in Thayet Town is called St Teresa Leprosy Home and it provides care to people affected by leprosy in the central part of the country. These colonies still accept new comers and provide a place of solitude for destitute cases having nowhere to go.

In addition to these colonies, the Ministry of Social Welfare during the late seventies opened 3 Child Care Centers for children of people affected by leprosy. These centers were opened in Htauk Kyant, Mandalay and Keng Tong. Off-springs of people affected by leprosy were housed and provided education in these facilities by the government. However, it was found later that this created a lot of social problems for the children and their parents especially when the children are not orphans. This

initiative was even seen to enhance discrimination by selectively treating these children as a special case. Around mid-seventies, these establishments were converted into a regular child care center by the Ministry of Social Welfare (Saw Lwin, Mg Saing and et al. , 2015).

Leprosy has been well known to be endemic in the Union of Myanmar for many centuries. However, the earliest scientific record regarding the magnitude of the leprosy problem in the country was first reported by the Leprosy Commission of India (1890–1891), as Myanmar at that time was included under India during British rule. In 1891, the Commission estimated the prevalence to be 8.6 per 10,000 population for the whole country. At the same time, the prevalence for Central Myanmar was reported as 14.4 per 10,000. The 1932 census of Myanmar reported eleven thousand one hundred and twenty-seven (11,127) leprosy cases (prevalence being 7.6 per 10,000 population) in the country, which was probably under estimate as the enumeration was based mainly on obvious and easily recognizable signs of the disease.

In 1951, Dr Santra a prevalence of 250 per 10,000 populations in the Mandalay area. It was estimated that about 100,000 cases could be present in the country and the prevalence at that time was estimated to be 50 per 10,000 populations. This estimation was revised and increased by Dr Lampe (WHO consultant to Myanmar from 1953 to 1955) to 100 per 10,000 population (about 200,000 cases).

A WHO Leprosy Advisory Team in 1963–1964 conducted a survey and revised the estimated prevalence upwards to 250 per 10,000 population for the whole country (about Myanmar 590,000 cases). In some areas of Central Myanmar, the prevalence was estimated to be as high as 400 per 10,000. During the time of this survey, the prevalence reported by the leprosy control project teams in Shwebo and Myingyan District was 322 and 443 per 10,000 populations, respectively. During 1973, the national authorities conducted a parallel survey which was called National Leprosy Programme Prevalence and Assessment Survey and in its report the prevalence was estimated to be 242 per 10,000 populations.

Myanmar has achieved the elimination of leprosy as a public health problem, new cases ranging from 2,000 to 3,000 are detected annually. At the end of 2017, there were two thousand two hundred and sixteen (2216) registered cases and the prevalence rate was 0.42 per 10,000 population. New Case Detection Rate (NCDR) for 2017 was (4.3 per 100,000). More than eighty percent (80%) of total new cases

were detected by PCD. Ninety percent (90%) of the new cases were detected from high disease burden areas (Ayeyarwaddy, Bago, Sagaing, Mandalay, Magway, Yangon Regions and Shan State).

In 2017, the situation was also noted as 76.7% MB proportion among new cases, 3.5% Child cases proportion, 3% to 5% were under 15 years of age,12.4% Disability Grade-2 among new cases and 5.25 per million pop Disability Grade 1 Rate. The MB proportion is slowly increasing especially when Case Detection Rate (CDRs) decrease. The proportion of women among new cases which has only been reported since 2005 remained stable at around 35%. Male and Female ratio was 2:1. The decline in CDR has slowed down since 2003 and has been completely stagnant for the past 4 years (4.7 per 100,000 in 2013). This decrease in case detection appears to have happened right across the country. As one might expect, this was accompanied by a slow decline in the proportion of children among new cases also (from 6.4% to 4.5%).

Table 3.1 Leprosy New Cases for Myanmar (2014-2016)

Region	2014	2015	2016	Grand Total
Mon	61	63	69	193
Yangon	354	296	314	964
Mandalay & NPT	466	424	450	1340
Magway	284	270	295	849
Ayeyarwaddy	299	251	281	831
Bago	385	279	328	992
Chin	8	7	3	18
Kachin	31	15	15	61
Kayah	6	4	10	20
Kayin	62	60	39	161
Rakhine	25	27	24	76
Sagaing	394	372	400	1166
Shan	244	220	201	665
Tannitharyi	31	28	15	74
Grand Total	2650	2316	2444	7410

Sources: Leprosy Control Programme,2018

The MB proportion is slowly increasing too, something that is often observed when CDRs decrease. The proportion of women among new cases has only been reported since 2005. It has remained stable at around 35%. Since MDT was started, release from treatment cases with MDT were more than 280,000. According to the reports of Prevention of Disability (POD) Project, disability proportion of leprosy affected persons was 30 to 35 %. Moreover, proportion of Disability Grade 2 (visible deformity) among new cases detected was more than 10% for the last five years.

Leprosy and its consequences are some complex human problems leading to discrimination, stigma and prejudices. Socio-economic problems of leprosy affected persons and their families may not be uncountable and immeasurable. Although the psychosocial and medical needs were not much prevalent among the clients, socio-economic rehabilitation activities targeted more towards RFT cases with older age and higher disability grade are needed. Quality of life (QOL) decreased progressively

in leprosy-affected persons whether or not they were on-MDT or RFT. Stigma was still obvious in some areas due to less HE activities (i.e. special activities) leading G-2 cases seemed to be hiding. Most of needs concerned were related to job that was affected by their disability. Social rehabilitation activities are needed to focus on target groups.

New cases detection trend was decreasing but there was still in apparent number of cases in recent years. Linear trend analysis showed about new cases detection was decreasing about 100 cases per year. Top areas of high and low endemicity according to NCD during the years were Mandalay, Sagaing, Bago, Ayeyarwady, Yangon, Magway and Shan. Although Mandalay Region was highest of all regions through the years, stability of trend was marked in Yangon. Highest decreasing trend was noticed at Ayeyarwaddy and Bago Regions (cases reduction rates were 28 and 23 per year).

Contact examination of leprosy affected persons who are taking MDT and who have been Released from Treatment (RFT) is already routine practice. Household contacts of all new cases are screened yearly up to 5 years after the index case has complete MDT. At the time of diagnosis, contact examination is done by specialized leprosy staff. Yearly Follow-up contact examination is done by Basic Health Staff (BHS). Leprosy Awareness Campaign (LAC) was conducted in 60 pocket health centers during 2015, 40 pocket health centers during 2016 and 60 pocket health centers during 2017. Pocket areas are still remaining. Inadequate Manpower is obvious at the moment. POD activities are also needed to be sustained.

3.2 National Health Policy in Myanmar

Policy guidelines for health service provision and development have also been provided in the Constitutions of different administrative period. The following are the policy guidelines related to health sector included in the Constitution of the Republic of the Union of Myanmar (2008).

(i) The union shall be earnestly strived to improve education and health of the people and enact the necessary law to enable National people to participate in matters of their education and health. (Article 28)

(ii) The union shall be Care for mothers and children, orphans, fallen Defense Services personnel's children, the aged and the disabled. (Article 32)

(iii) The union shall be Mothers, children and expectant women shall enjoy equal rights as prescribed by law. Every citizen shall, in accord with the health policy laid down by the Union, have the right to health care. (Article 367)

The National Health Policy was developed with the initiation and guidance of the National Health Committee in 1993. The National Health Policy has placed the Health for All goal as a prime objective using Primary Health Care approach. The National Health Policy is designated as follows:

(i) To raise the level of health of the country and promote the physical and mental well-being of the people with the objective of achieving "Health for all" goal, using primary health care approach.

(ii) To follow the guidelines of the population policy formulated in the country.

(iii) To produce sufficient as well as efficient human resource for health locally in the context of broad frame work of long term health development plan.

(iv) To strictly abide by the rules and regulations mentioned in the drug laws and by laws which are promulgated in the country.

(v) To augment the role of cooperative, joint ventures, private sectors and non-governmental organizations in delivering of health care in view of the changing economic system.

(vi) To explore and develop alternative health care financing system.

(vii) To implement health activities in close collaboration and also in an integrated manner with related ministries.

(viii) To promulgate new rules and regulations in accord with the prevailing health and health related conditions as and when necessary.

(ix) To intensify and expand environmental health activities including prevention and control of air and water pollution.

(x) To promote national physical fitness through the expansion of sports and physical education activities by encouraging community participation, supporting outstanding athletes and reviving traditional sports.

(xi) To encourage conduct of medical research activities not only on prevailing health problems but also giving due attention in conducting health system research.

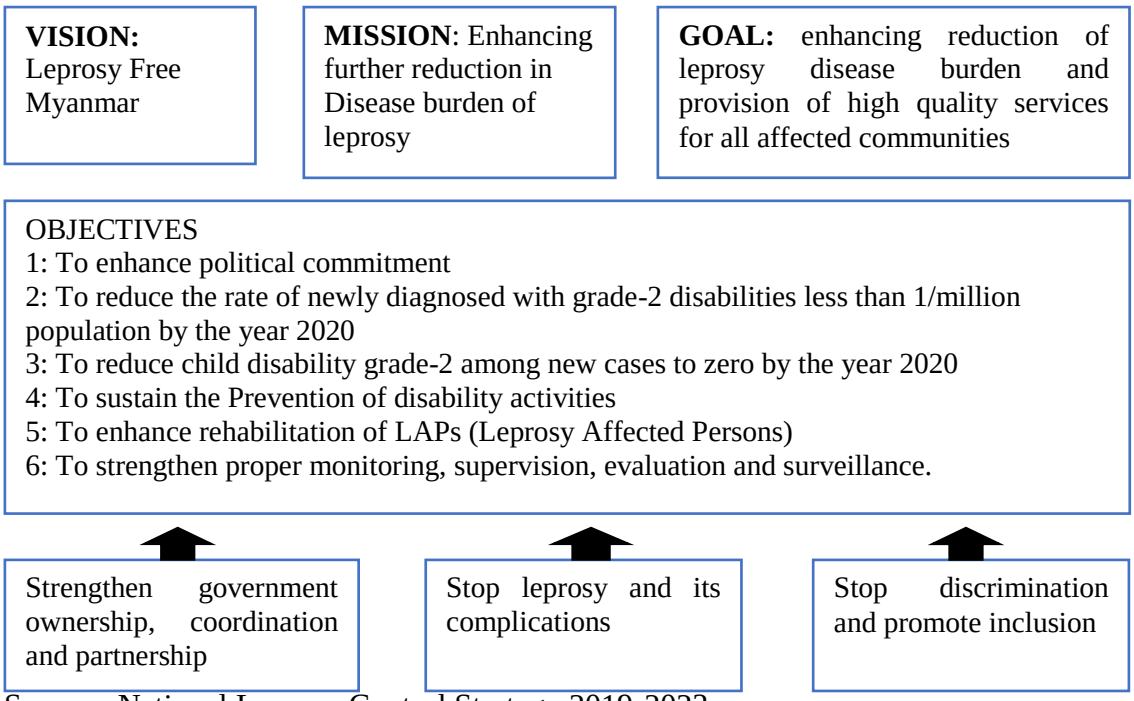
(xii) To expand the health service activities not only to rural but also to border areas so as to meet the overall health needs of the country.

(xiii) To foresee any emerging health problem that poses a threat to the health and well-being of the people of Myanmar, so that preventive and curative measures can be initiated.

(xiv) To reinforce the service and research activities of indigenous medicine to international level and to involve in community health care activities.

(xv) To strengthen collaboration with other countries for national health development.

Figure 3.1 Framework of National Leprosy Control Strategy (2019-2023)



Source: National Leprosy Control Strategy 2019-2023

The National Leprosy Conference was held at the Myanmar International Convention Centre-II in Nay Pyi Taw in December 31, 2019, with the motto 'join hands to stop discrimination'. State Counsellor Daw Aung San Suu Kyi said "efforts to eradicate discrimination against leprosy patients and their families should be given a top priority in combating the disease in Myanmar." She also stressed the need to step up efforts for dissemination of knowledge on leprosy among the people so that people have the right attitude towards leprosy patients, as the country is seeing discrimination against patients and their families and incorrect attitudes have impacted the daily life of patients.

The leprosy control in all the WHO global strategies over the past 3 decades has been detection of all cases and prompt treatment with multidrug therapy (MDT). As the global target has been reached in all but a few countries, the most recent strategy indicates a shift from “elimination of leprosy as a public health problem”1 to reduction of the disease burden, measured as a reduction in grade-2 disabilities (G2D) among new cases and new cases in children. The Global Leprosy Strategy 2016−2020, “Accelerating towards a leprosy-free world”,2 was adopted by most countries in which leprosy is endemic and which designed national implementation plans as envisioned in the strategy. The Global Leprosy Strategy 2016−2020 is based on 3 pillars: (i) strengthen government ownership, coordination and partnerships; (ii) stop leprosy and its complications; and (iii) stop discrimination and promote inclusion. The 3 principal targets for 2020 are 0 new child cases with G2D, <1 per million population new leprosy cases with G2D and 0 countries with laws or legislation that allow discrimination against people with leprosy. For the first time, a target was set to measure reduction of discrimination against leprosy and the people affected by the disease (WHO, 2017: reducing the disease burden due to leprosy, 2018,Aug,31)

3.2.1 Government Implementation in the Leprosy Programme

Myanmar Leprosy Control Programme was launched in 1952. Partial integration with People's Health Plan started in 1977. In 1988, WHO recommended MDT service was started in six hyper endemic regions (Yangon, Mandalay, lower Sagaing, Magway. Ayeyawady and Bago) and it was fully integrated into Basic Health Services in 1991. MDT services covered the whole country in 1995. Myanmar has achieved Leprosy Elimination Goal at the end of January 2003. It means that the registered prevalence rate per 10,000 populations is less than one.

Before introduction of MDT services, registered prevalence rate was 54.3/10,000 in 1987. Prevalence rate was obviously reduced at the end of 2013 (0.45/10,000). Total registered cases at the end of 1987 were 204,282 and it reduced significantly to 2,721 at the end of 2013. A total of 289,661 leprosy cases have been treated with MDT and cured since 1988.

After achieving elimination of leprosy, leprosy control activities have been sustained to reduce the burden due to leprosy. In 2010, National strategies for leprosy control were developed based on "Enhanced Global Strategy for Reducing the

Disease Burden due to Leprosy (2011- 2015) and National Guidelines (2011- 2015) was also developed based on WHO Operational Guidelines.

Case finding activities and treatment with MDT are being carried out by Basic Health Staff with technical support of leprosy control staff. Dissemination of knowledge on leprosy is carried out through various medias with emphasis on early signs and symptoms, curability, availability of free- of- charge MDT drugs and prevention of disability by early diagnosis and treatment. Training on Leprosy Control for Newly Promoted Assistant Leprosy Inspectors was conducted in Yenathar Leprosy Hospital. Capacity building of Township Focal Persons for Leprosy Control were conducted in Sagaing, Magway, Ayeyarwady, Bago Regions and Chin, Rakhine, Shan State (East), Shan State (North).

Since achieving the leprosy elimination goal, the programme emphasized more on prevention of disability and rehabilitation. At the end of the year 2013, prevention of disability activities (POD) are being carried out in 147 townships with regular follow up case assessment, self-care training and provision of necessary drugs, aids and services. Leprosy Control Programme has planned to expand POD activities in the remaining townships of high disease burden areas (Yangon, Mandalay, Sagaing(lower), Ayeyarwaddy and Bago). In 2013, training on Prevention of Disability due to leprosy were conducted in 5 townships in Yangon Urban area and 10 townships in low disease burden areas (Kachin, Kayin, Kayah, Chin, Shan States and Tanintharyi Region).

Meeting on Strengthening Leprosy Control and Prevention was conducted in Nay Pyi Taw. According to the recommendation of this meeting, Technical Advisory Group (TAG) for leprosy control was formed and first TAG meeting was conducted in July, 2013. Activities implemented in 2013 are as follows:

a. Sustaining political commitment
b. Case finding and MDT services throughout the country
c. Community awareness raising activities including printed and electronic medias
d. Leprosy Awareness Campaign conducted in 6 pocket townships, Sagaing Region
e. Meeting on Strengthening Leprosy Control and Prevention
f. Technical Advisory Group (TAG) for leprosy control and first TAG meeting was conducted

g. Meetings for planning, implementation and evaluation for Leprosy Control Activities
h. Monitoring and Supervision at different level
i. Capacity building of township focal persons for Leprosy Control
j. Workshop on capacity building of health supervisor for leprosy control
k. Training on Leprosy Control for Newly Appointed Team Leader
l. Training on Leprosy Control for Newly Promoted Assistant Leprosy Inspectors
m. Workshop on development of National CBR Guideline (Health Component) for Leprosy Affected Person
n. Expansion of Prevention of Disability project in 10 townships
o. Training on Prevention of Disability and self- care for BHS and baseline POD assessment in 10 expanded townships
p. Training on Prevention of Disability for BHS in 5 urban townships
q. Training on Prevention of Disability for BHS in 10 townships in Low disease burden areas
r. Follow up assessments in previous POD townships
s. Research activities mainly focused on strengthening participation of leprosy affected person in leprosy control services and reduction of Grade- 2 disability among new cases

The World Health Organization (WHO) says leprosy is a chronic but not highly infectious disease. Leprosy can be cured. In the last two decades, 16 million people with leprosy have been cured. The World Health Organization provides free treatment for all people with leprosy. Treatment depends on the type of leprosy that you have. Antibiotics are used to treat the infection. Long-term treatment with two or more antibiotics is recommended, usually from six months to a year. People with severe leprosy may need to take antibiotics longer. Antibiotics cannot treat the nerve damage. Anti-inflammatory drugs are used to control nerve pain and damage related to leprosy. This may include steroids, such as prednisone. Patients with leprosy may also be given thalidomide, a potent medication that suppresses the body's immune system. It helps treat leprosy skin nodules. Thalidomide is known to cause severe, life-threatening birth defects and should never be taken by women who are pregnant or women who may become pregnant.

3.2.2 The Leprosy Programme Implementation in International / Local Non-Government Organizations

American Leprosy Mission, the Leprosy Mission (TLM) and Myanmar Christian Leprosy Mission (MCLM) has been active in Myanmar for over one hundred and twenty years that supporting local Christian organizations including the leprosy colony. This program is for the people affected by leprosy and disability to overcome barriers such as delayed access to health services, lack of access to private and public spaces, and the ignorance and discrimination that prevent their full participation and acceptance in society.

This organization strengthens people to stand on their own and speak up about issues related to their lives and communities. Strategically located Disability Resource Centers are focal points for rehabilitation for all kinds of disability and give it is a presence in all the regions with highest prevalence of leprosy, helping to ensure new cases are detected and treated in a timely manner. The organization has a strong voice to influence changes in regard to leprosy and disability issues in the public arena of Myanmar. They are now helping in Muse, Kengtung, Tachileik, Yenanthar, Minbu, Thayet, Letpadan, Pathein, Mayanchaung and Mawlamyine.

Leprosy Control Programme was launched in 1952. Partial integration with People's Health Plan started in 1977. In 1988, WHO recommended MDT service was started in six hyperendemic regions (Yangon, Mandalay, lower Sagaing, Magway. Ayeyawady and Bago) and it was fully integrated into Basic Health Services in 1991. MDT services covered the whole country in 1995. Myanmar has achieved Leprosy Elimination Goal at the end of January 2003. It means that the registered prevalence rate per 10,000 populations was less than one.

3.3 Historical Background of Kengtung Township

Keng Tung is the capital of Eastern Shan State in Myanmar. The total population is 171.620, Male is 8,7779, Female is 83,841 and male ration is alittle more than female is 105. Urban population is 25.8% and township area is 3,783.7 Km2. Keng Tung formed 5 wards and over 300 villages of 31village tracts. Urban population is 162,222 and rural population is 34,096. The high sea level is 776m, 2545.93ft, 30551.2in, Latitude is 21□ 17' 29" North and Longitude is 99□ 36' 15"East (Myanmar City Population, 2014). Keng Tung is the capital of Eastern Shan State and they are 3 districts of Keng Tung,Tachileik and Mong Sat. It is far from 740

miles of Yangon. Keng Tung is Shan King (Saw Bwa) built in Keng Tung since 13th century and there has Shan, Akha, Akhi, Lahu, Wa, Palung, Loi, Kachin and many ethnics people stay in Keng Tung. it is located in an easily available location to the "golden triangle" area, close to the border with China, Laos and Thailand. The religions are Buddhist, Christian, Islam, Hindu, Animist, other religion and non-religion. Kengtung has several lakes, the largest, Naung Tung Lake, located in the western part of the city, followed by Naung Kham Lake and Naung Yarng Lake to the south of the Kentung Roman Catholic Mission. The town is surrounded by beautiful forests and mountains. Keng Tung central market is the half day market that is located in the downtown area and it brings down many ethnic villagers from the surrounding mountains every morning. Keng Tung lies in the valley between the high misty mountains of the Shan Plateau and the Mekong and the Than Lwin rivers. It has the exotic tribe villages, the decaying colonial buildings, the old-style houses with the wooden balconies depicting the Shan architecture and ethnic belief, and the magnificent mountains. Every trait in Keng Tung remains rustic, pristine, and scenic.

The Weather Condition of Keng Tung Township: Keng Tung weather is a tropical wet and dry/ savanna climate with a pronounced dry season in the low-sun months, no cold season, and wet season is in the high-sun months. Temperatures are very warm throughout the year, although the winter months (December–February) are milder and nights can be quite cool. There is a winter dry season (December–April) and a summer wet season (May–November). The rainfall probably averages between 50 and 60 inches (1.5 m) for the year. The temperature seems to rise to nearly 38 °C (100 °F). During hot weather, falling to 21 °C (70 °F) or less during the night. In cold weather a temperature of 4 °C (40 °F) or a few degrees more or less appears to be the lowest experienced (Scott, 1900-1901).

Health and Education Situations in Keng Tung Township: General Hospital, 300 bed Military Hospital, one private hospital and many clinics in Keng Tung. Education is easy to assess studying and there have 3 Universities of Keng Tung University, Computer University and Technological University.

Transportation and Communication: Keng Tung is located on the National Highway 4 (NH4) and at the AH2 and AH3 of the Asian Highway. Now, communication is accessible using Telenor, MPT, CDMA, Thai phone and Chinese phone.

Livelihood Situation: The main working is agriculture. In Keng Tung Township, are the proportion of employed persons working in the industry of “Agriculture, forestry

and fishing" is the highest with 61.4 per cent. There are 63.0 per cent of males and 59.1 percent of females working in "Agriculture, forestry and fishing" industry. There is also a few Lacquer Wares Workshops that produce the items in unique designs only seen here in the Eastern Shan State.

Economics Situation: The existence of minerals was reported by the sawbwa, or chief, to Francis Garnier in 1867, but none is worked or located. Gold is washed in most of the streams. Teak forests exist in Mong Pu and Mong Hsat, and the sawbwa works them as government contracts. One-third of the price realized from the sale of the logs at Moulmein is retained as the government royalty. There are teak forests also in the Mekong drainage area in the south of the state, but there is only a local market for the timber. Rice, as elsewhere in the Shan States, is the chief crop. Next to it is sugarcane, grown both as a field crop and in gardens. Eai-th-nuts and, tobacco are the only other field crops in the valleys. On the hills, besides rice, cotton, poppy and tea are the chief crops. The tea is carelessly grown, badly prepared, and only consumed locally. A great deal of garden produce is raised in the valleys, especially near the capital. The state is rich in cattle, and exports them to the country west of the Salween. Cotton and opium are exported in large quantities, the former entirely to China, a good deal of the latter to northern Thailand, which also takes shoes and sandals. Tea is carried through westwards from Keng Hung, and silk from the Siamese Shan States. Cotton and silk weaving are dying out as industries. Large quantities of shoes and sandals are made of buffalo and bullock hide, with Chinese felt uppers. There is a good deal of pottery work. The chief work in iron is the manufacture of guns, which has been carried on for many years in certain villages of the Sam Tao district. About the currency they are using Myanmar Kyats, Bath (Thai), Silver Money (Colony), Yum (China) and Kip (laos) (Scott, James George, 2015).

3.4 Brief of Naung Kan Leprosy Colony

Keng Tung people are calling Naung Kan village or Leprosy Colony Naung Kan. Naung Kan located in of Keng Tung, 5miles, near the GTI University in Loi Mwe Road. Leprosy causes extreme disfiguring to the nerves and skin. It's one of the world's oldest and most feared diseases. Many still think it's highly infectious, while in truth it's now truly estimated that more than 95 percent of the world's population immune to mycobacterium leprae, the bacterium that causes leprosy. Shortly after the Second World War, Father Cesare Columbo took over the Naung Kan from the

American Baptist Mission. He wanted to make a place where those afflicted by leprosy could live out productive lives alongside their families, a radical concept for its time. In the mid-1960s, after the dictatorship took control of the country several years, Father Columbo and the Italian sisters who cared for residents at the colony were deported. But local Catholic sisters took their place to continue caring for the residents.

Currently, there are 59 former leprosy patients here; all of them have been cured multi-drug therapy. Yet they continue to live at Naung Kan with their family members, approximately 300 people in all. Most of the residents at Naung Kan have lived at the colony with their families for several decades, some even longer. They come from different ethnic minorities with distinct cultures and languages, but they all are now part of an intact community, after being ostracized from their own communities in so many years ago. (Dr.Tin Shwe & Brother Than Tin, 1983), (William, 1951)

CHAPTER IV
SURVEY ANALYSIS

This chapter was studied on demographic characteristics of the Socio Economic affected by leprosy people's knowledge, their rights and registration, practice on health care. Demographic characteristics of all the 123 households are collected and analyzed.

4.1 Survey Profile

In Mong Latt village tracts, there are 1. Wan Tone village 2. Wan Lern 3. Wan Sar 4. Naung Kan 5. Wan Mai 6. Wan Taung 7. Wan Yang 8. Wan Kyawn 9. Wan Kan 10. Pansakya 11. Pharnada. Among them, Naung Kan village is selected for the challenges and barriers of leprosy people. The survey design followed by organized result of data analyses, focus group discussion (FGD) and key information from face to face interviews with leprosy people, their family, village head, Sisters of Charity and Keng Tung Hospital. It was analyzed between April 2008 to May 2019 and the study all collected 123 Household in Naung Kan Village.

4.2 Survey Design

Using both qualities and quantitative data analysis method and data was collected through structured questionnaire for the research as a main tool for the study. In survey questionnaires contain five parts was design for this study. Part I is related the primary information about the socio-economic demographic characteristic of the sampled individuals and timeline of leprosy colony. Part II is described the conditions of healthiness in the village. Part III is the conditions of educational services in the village. Survey analysis of social issue in the village is in the Part IV. Part V is about conclusion consisting of key findings and suggestions of the study.

The collected data was first coded, edited and tabulated to ensure consistency and competence. This was done by entering data into a computer through excel spreadsheet to enable management of the data before computing and shown in

frequency percentage.

4.3 Analysis on Survey Data

4.3.1 Socio-Economic and Demographic Characteristics

Leprosy effected people of socio economic may depend on socio-demographic characteristic of respondents. In descriptive analysis on socio-demographic factors of 123 houses, Male(36) and Female(84) in the survey, number and percentage distribution on age, race, religion, education level, occupation, family members, and monthly income are included.

Table 4. 1 Demographic Characteristic of Respondents

Characteristics		M	F	Respondent	Percentage
Age in Years	<15years	0	0	0	0.0
	16-30 years	8	6	14	11.4
	31-54 years	23	32	55	44.7
	55-65 years	9	16	25	20.3
	>66 years	13	16	29	23.6
	Total	53	70	123	100
Races	Shan	20	31	51	41.5
	Akha	14	22	36	29.3
	Lahu	10	11	21	17.1
	Palaung	1	3	4	3.3
	Others	5	6	11	8.9
	Total	50	73	123	100
Religion	Buddha	8	7	15	12.2
	Christian	45	63	108	87.8
	Hindu	0	0	0	0.0
	Muslim	0	0	0	0.0
	Others	0	0	0	0.0
	Total	53	70	123	100

Source: Survey data, 2019

Table 4.1 Demographic Characteristic of Respondents (Continuous)

Characteristics		M	F	Respondent	Percentage
Education level	Graduate	2	4	6	4.9
	University	1	2	3	2.4
	High School Level	26	35	61	49.6
	A Thone Lone	11	9	20	16.3
	Illiteracy	15	18	20	26.8
	Total	55	68	123	100
Family members	2 to 5 members	42	53	95	77.2
	6 to 10 members	11	14	25	20.3
	10-12 members	2	1	3	2.4
	Total	55	68	123	100
Monthly Income	<150,000	35	34	69	56.1
	150,000 - 250,000	5	18	23	18.7
	250,000 - 300,000	4	10	14	11.4
	Above 300,000	1	2	3	2.4
	No Income	8	6	14	11.4
	Total	53	70	123	100

Source: Survey data, 2019

According to Focus Group Discussion (FGD), Naung Kan village in (123) Households, Male (36) and Female (48). As shown in Table 4.1, 123 of representing households are 28% of Shan, 34.3% of Akha, 28.9% of Lahu and 1.8% of others. Christian is the majority (84%) and Buddhist is (16%). The education level based on 123 of representing household respondents are 2.3% of graduate, 4.3% of University, 40% Basic High School,25.8% of A Thone Lone and 27.8% of A Thone Lone. According to the data from households, 38.6% growing shifting cultivation, 5.2% of growing paddy field,2 % of growing gardening, 3.4% of doing home gardening and 50.8% of others like vendors, construction workers, daily workers, dependents, government staffs, company staffs, and small merchants etc.., The average of family members in one household has between 3 and 4 members. Moreover, the average monthly income of one household has ranging from 200,000 to 250,000 Kyats.

By Focus Group Discussion, the brief history about Naung Kan village is in follow. At first, Msgr.Bonetta and 3 leprosy peoples started at St.Joseph leper hospital

in Yan Kham of Keng Tung since 1923. During 5years, over 149 leprosy patients were increasing more and more. Father. Colombo, the doctor, the American Baptist Missions, asked land from Sawba Sao In Ta Lieng and built Naung Kan, Leprosy home and hospital in 1934. (leprosy colony data) In 1940, the number of leprosy patients are six hundred and nine (609) that can see from chapter 3. Last ten years ago, over hundred leprosy patients were in Naung Kan village. In current situation, Sister of Charity keep on caring fifty-nine (59) leprosy patients. Most of the people who suffer from leprosy disease came from Eastern Shan State such as Mong Lin, Mong Sat, Ha Ka, Mong Hoi, Mong Lin, Ban Mai, Hawa, Santa Maria and border area of China. Those people who from Shan, Lahu and Mountain region are occurred disease but Akha people are hardly occurred.

Table 4. 2 Livelihood Conditions

	Respondent	**Percentage**
Agriculture		
Shifting cultivation	8	6.5
Paddy field	44	35.8
Gardening	11	8.9
Home gardening	14	11.4
Others (bamboo handicraft)	46	37.4
Animals Husbandry		
Poultry/ducks	39	31.7
Pig	20	16.3
Buffalo	18	14.6
Fish pond	7	5.7
Others	15	12.2

Source: Survey Data, 2019

	Respondent	**Percentage**
Others		

Construction worker	15	12.2
Daily worker	19	15.4
Handicraf	6	4.9
Begger	7	5.7
Others	10	8.1

Source: Survey Data, 2019

As shown in Table 4.2, it includes three main parts are agriculture, animal husbandry, and other fields. In agriculture,6.5 % of paddy are growing shifting cultivation, 35.8% of growing paddy, 8.9% of growing gardening, 11.4% of doing home gardening and 37.4% of others like value added products. In animal husbandry, 31.7% of poultry and ducks, 16.3% of pig, 14.6% of cows and buffalos, 5.7%of fish ponds and 12.2% of other like value-added products. Besides, 12.2% constructed workers, 15.4% daily worker, 4.9% of handicraft, 5.7% of beggar and 8.1% of other fields like migrant workers, government staffs, company staffs, motorbike workshop, tri-car carry, and small merchant. Some are migrants working in border area of Tachileik, Thailand and Mong Lar.

By their answering of livelihood conditions, small brokers and merchants are collected the paddy, seasonal fruits and vegetables such as penants, corns, mustard, and pineapple. Most of the products are selling in Mong Lar township (border area of China). Some of the seasonal vegetables are sold around the villages by motorbike or foots and some products are sold in the township market. And also, the brokers are brought fish from the fish ponds in one time.

Table 4. 3 Monthly Income of Respondents

Monthly Income	Respondent	Percentage
< 150,000	69	56.10
150,001 - 250,000	23	18.70
250,001- 300,000	14	11.38
Above 300,000	3	2.44
Monthly Income	**Respondent**	**Percentage**

No Income	14	11.38
Total	123	100

Source: Survey Data, 2019

In table (4.3), which was divided into five layers of income, under 150,000kyats, between 150,000 and 250,000 kyats, between 250,000 and 300,000kyats, above 300,001kyats and there has no income. The lowest income of people is 150,000 (56.10%) and the highest income of a few people is above 300,001 (2.44%). The middle range is between above 150,001 to 250,000(18.70%) and 250,001 to 300,000 (11.38%). 11.38% of the respondents have no regular income and they get regular supported by Missionary.

Table 4. 4 Monthly Expenditure of Respondents

Monthly Expenditure	Respondent	Percentage
<150,000	64	52.0
150,001 - 250,000	26	21.1
250,001 - 300,000	16	13.0
Above 300,001	4	3.3
Total	123	100

Sources: Survey data, 2019

In table (4.4), which was divided into five layers of income, under 150,000kyats, between 150,000 and 250,000 kyats, between 250,000 and 300,000kyats, above 300,001kyats The lowest expenditure of people is 150,000 (52%) and the highest expenditure of a few people is above 300,000(3.3%). The middle range is between 150,000 to 250,000(21.1%) and 250,000 to 300,000 (13%).

By comparing table (4.3) and table (4.4), income and expenditure, it shows that expenditure is more than income. The reasons are business crises, solving health problems like suffering from leprosy disease, HIV/AIDS, TB and diabetes.,etc.

4.3.2 The Health Condition in the Village

Table 4. 5 Taking Treatment Condition of Leprosy Affected People

Taking Treatment Condition	Respondent	Percentage

Completed	35	59.3
Not completed	24	40.7
Total	59	100

Source: Survey Data, 2019

Table (4.5) is shown the situation of leprosy patients who received treatment in Naung Kan Village. Currently, 13.3%of this village in leprosy patients is Male 27, Female 32, and Total 59. According to the survey result, some of the patients are very old. Since 1948, there were many patients until now in the leprosy colony. As a discussion, five new leprosy patients found per year last 10years ago. Currently, only one new leprosy patient found per five years. According to the discussion of Leprosy Campaign Leader of Keng Tung Hospital, migrant workers (Central of Myanmar) and mountain regions have occurred leprosy diseases. From his experience, leprosy disease also can occur even in three months infants to ninety-five ages.

All of the patients get treatment regularly in Leprosy Colony Hospital and Keng Tung Hospital. Based on the patient there are three kinds of treatment like six months of treatment, one-year treatment, and around three years of treatment. Among fifty-nine leprosy patients, seven leprosy patients who are fixed artificial leg in Keng Tung Hospital connecting by Sisters of Charity (Leprosy colony) and twenty patients of leprosy who got pairs of crutches. Among the fifty-nine patients, 59.3% of leprosy people who are completed and 40.7% of leprosy patient who are uncompleted.

4.3.3 Educational Attainment of Respondents

Table 4. 6 Educational Attainment of Respondents

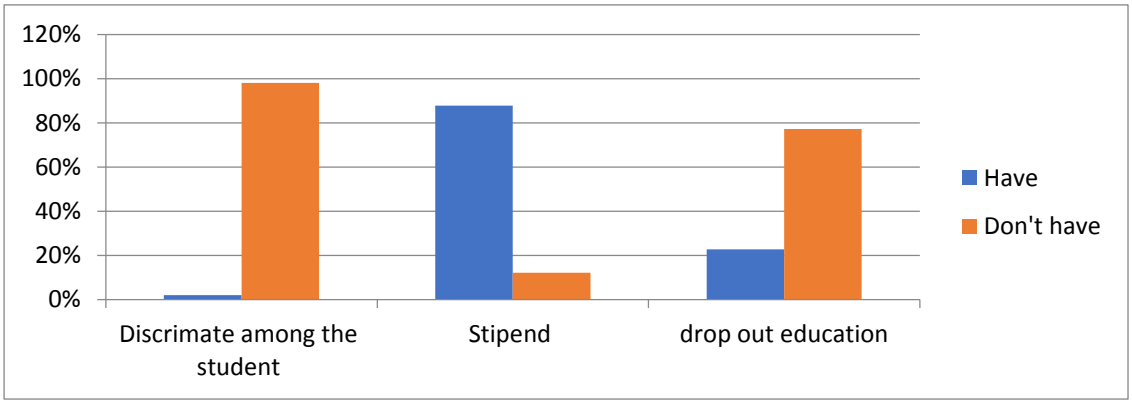
Education Level	Number of Respondent	Percentage
Graduate	6	4.9
University	3	2.4
Basic High School	61	49.6
A Thone Lone	20	16.3
Illiteracy	33	26.8

Source: Survey Data, 2019

Table (4.6) is shown the condition of educational attainment of respondents in the village. The education level is based on 123 of representing household respondents are 2.30% of graduate,4.30% of University, 40% of Basic High School

level, 25.70% of illiteracy and 27.80% are others such as A Thone Lone, informal learning and kindergarten. As the discussion, primary school has been built after the age of independence and now, upgrade to middle school in 2004 and the nursery school was built by World Vision Myanmar with around 200 students including other villages. After the middle school, they are attending Basic Education High School in Keng Tung Township by village head arrangement. After completing High School level, they can learn Keng Tung University, Computer University and Government Technology Institute (GTI) according to the High School result. It is far from high school and university to village about 6 or 7 miles except GTI. When they all are studying, there has no discrimination and criticize about the leprosy effected people and they all are help each other for learning together, participating group work and sharing lesson learn.

Figure 4.1 Discriminate and Social Conditions

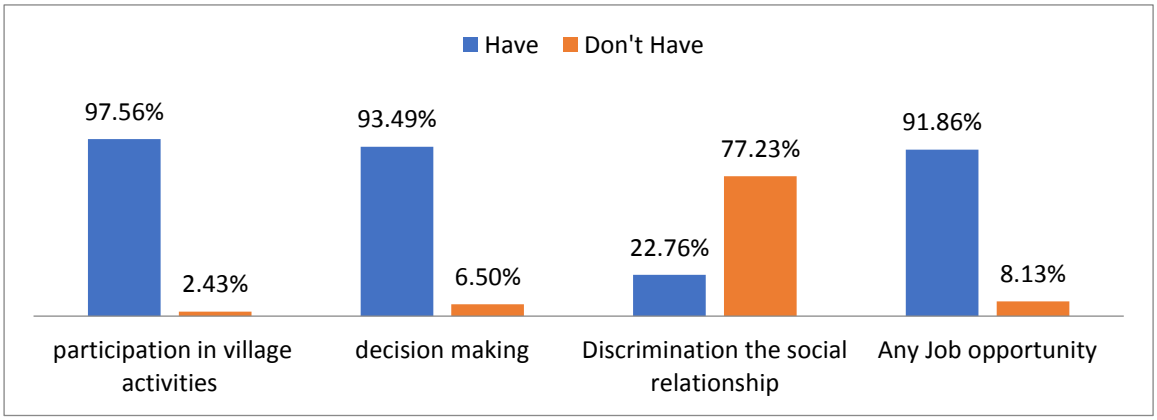


Source: Survey Data, 2019

According to the figure (4.1), there has 59% of the students do not have discrimination among the student and external factors. 41% respondents do not know about their children who have discrimination among the student in school. 88% of the High School students and University students get stipend from missionary, other donors and the students got material aid like text books, exercise book and stationary from the government side expect 12% of students. 23% of students drop out of school because they are not language barrier, low interesting, willing to learn, may not be the first priority and family business crisis. 77% of the students are still learning their education.

4.3.4 The Conditions of Social Issue in the village

Figure 4.2 The Condition of Social Issue in the Village



Source: Survey Data, 2019

As shown in Figure (4.2), fifty-nine leprosy people from one hundred and twenty-three household can participate village's activities are 97.56% and 2.43% cannot have participants for bad stage of leprosy disease. 93.49% can do decision making in meeting. 77.23% have discrimination in the social relationship but 22.76% have discrimination in the social relationship and banish them from their native village last early 20 decades. 98.37% of the leprosy family members can get job opportunities by applying government office, company, and other business sectors. However, fifty-nine leprosy people worked in their own job in a village such as agriculture, animal-husbandry, and other value-added products except from ten leprosy patients. Ten leprosy patients of 8.13% are fully supported by the sister of charity such as regular health treatment, nutrition support, and other materials.

4.3.5 Awareness of Supporting and Services from Government and NGO

(a) Receiving Services from Government

Table 4. 7 Health Service from Government

Health Service from Government	Yes		No		Don't know	
	#	%	#	%	#	%
Awareness campaign	123	100	0	0	0	0
Leprosy treatment	59	47.97	64	52.03	0	0
Material Support	59	47.97	64	52.03	0	0

Health Service from Government	Yes		No		Don't know	
	#	%	#	%	#	%
Family planning	60	48.78	46	37.39	17	13.82
Others	90	73.17	33	26.83	0	0

Source: Survey Data, 2019

As shown in table (4.7) of government supports, all one hundred and twenty-three respondents got leprosy awareness and prevention from government. From all of them, 47.97% of fifty-nine leprosy patient got leprosy treatment (once a month) and regular follow up in leprosy colony by government and also fifty-nine leprosy patients are got material support from the government. Moreover, 48.78% of leprosy family members and leprosy patients got family planning, 73.17% of other health care service is shown in Part II, the conditions of healthiness in the village. Moreover, other donors gave them clothes, foods, medicine, money via from Sisters of Charity.

Table 4. 8 Education Service from Government

Education Service from Government	Yes		No		Don't know	
	#	%	#	%	#	%
Material support for children	13	10.56	110	89.43	0	0
ECCD awareness campaign	70	56.91	53	43.08	0	0
Scholarship program	0	0	50	40.65	73	59.50
Supporting building	11	8.94	0	0	112	91.05
Others	17	13.82	75	60.97	31	25.20

Source: Survey Data, 2019

Showing at the table (4.8), 10.56% of children in one hundred and twenty-three households received school material of text books, exercise books and stationary. 56.91% of Naung Kan leprosy colony people who parents, village leaders, influencer got Early Child Care Development(ECCD) awareness campaign. 59.50% of respondents did not know about scholarship program and 40.65% of respondents got these support from the above answers.

According to respondents' answers, 8.94% of leprosy people have got supporting school building, furniture nursery school, upgrade primary school to

middle school by a partial supporting of government for 5years ago. Knowing of government implementation such as health care service, nutritious project, personal hygiene training for students by 13.82% of respondents. Moreover, other donors gave them stationary, scholarship program from Sisters of Charity.

Table 4. 9 Village Development Service from Government

Village Development Service from Government	Yes		No		Don't know	
	#	%	#	%	#	%
Awareness of rural development	80	65.04	43	34.95	0	0
Supporting for drinking tank, well	109	88.61	14	11.38	0	0
Supporting Latrine	70	56.91	53	43.08	0	0
Village road or bridge	90	73.17	33	26.82	0	0
Others	90	73.17	13	10.56	20	16.26

Source: Survey Data, 2019

Table (4.9) is shown in the village development program, 65.04% of respondents are getting awareness of rural development by government organization. By answering the 88.61% of respondents, the government provided a public drinking tank, well for the village. 56.91% of respondents got the awareness of health care service although 43.08% of respondents did not get supporting latrine by their answers. 73.17% of respondents answer that there is a Mya Sein Yawn project by government that supports village fund for rural development knowing via data.

(b) Receiving Services from Non-Government Organizations

By group discussion in table (4.10), Naung Kan village had been got health education, village development and education by Non-Government Organization such as World Vision Myanmar (2009-2016), Maltesar International Organization (2016 to 2019), World Fish Program (2017-2019), PSI (2000-2019), GIZ (2014-2019).

Table 4. 10 Health Service from Non-Government Organizations

Health Service from NGO	Yes		No		Don't know	
	#	%	#	%	#	%
Awareness campaign	0	0	123	100	0	0
Leprosy treatment	59	47.97	64	52.03	0	0

Material Support	59	47.97	64	52.03	0	0
Family planning	60	48.78	46	37.39	17	13.82
Others	90	73.17	33	26.83	0	0

Source: Survey Data, 2019

As shown in table (4.9), by answering one hundred and twenty-three respondents, they did not get leprosy awareness in specialize but they got HIV/AIDS, TB, Malaria, Family planning awareness and prevention from Non-Government Organization. Fifty-nine of leprosy people (47.96%) got leprosy treatment from government and material support from Sisters of Charity. 48.78% women represented of one hundred and twenty-three respondents who got family planning, maternity support by other donors. 73.17% of villagers represented one hundred and twenty-three respondents who got health care services and support in TB, HIV/AIDS, Malaria. For example, the patients of TB, Malaria, and HIV who got a medical checkup, treatment, charges of hospital and nutrition support especially in HIV/AIDS, were being supported mother and child prevention. Moreover, Non-Government Organization gave awareness training like Anti-Human Trafficking training, HIV/AIDS prevention training, TB and Malaria awareness.

Table 4. 11 Education Service from Non-Governnment Organizations

Education Service from NGO	**Yes**		**No**		**Don't know**	
	#	%	#	%	#	%
Material support for children	13	10.56	110	89.43	0	0
ECCD awareness campaign	70	56.91	53	43.08	0	0
Scholarship program	4	3.25	119	96.74	0	0
Supporting building	102	82.92	21	17.07	0	0
Others	17	13.82	75	60.97	31	25.20

Source: Survey Data, 2019

Showing at the table (4.11), 10.56% of children in one hundred and twenty-three households got school material of bag, umbrella, school uniform, text books, exercise books and stationary. 56.91% of parents in one hundred and twenty-three households got Early Child Care Development awareness. 3.25% of High School Students received scholarship program from Non-Government Organization.

According to respondents' answers, supporting school building, furniture, nursery school, upgrade primary school to middle school along the end of the project last 3years. Knowing of Non-Government implementation such as health care service, nutritious project, personal hygiene training for students by 13.82% of respondents.

Table 4. 12 Village Development Service from Non- Government Organizations

Village Development Service from NGO	Yes		No		Don't know	
	#	%	#	%	#	%
Awareness of rural development	70	56.91	53	43.08	0	0
Supporting for drinking tank, well	123	100	0	0	0	0
Supporting Latrine	70	56.91	53	43.08	0	0
Village road or bridge	90	73.17	33	26.82	0	0
Others	90	73.17	13	10.56	20	16.26

Source: Survey Data, 2019

Table (4.12) is shown in the village development program, 56.91% of respondents have been receiving rural development by Non-Government organizations like World Vision Myanmar, Malteser(World Fish) and PSI. By answering of respondents, they got drinking tank (common) in their village that supported by World Vision. In addition, 56.91% of respondents got World Vision and Malteser provided latrine and medicine. 73.17% of respondents got partial supporting of village road or bridge from Non-Government Organization and 26.82% of respondents answered "No" means that they are also a part of contribution for village road or bridge by themselves (village development fund). Via from Focus Group Discussion and Key Indepth Interview, receiving sixty-five rice bags for child fund in 2009 and receiving one hundred and twenty-five rice bags for natural resources fund in 2013. 73.17% of respondents got it supported vocational training such as sewing, making jam training and handicraft Department of Social Warefare organized by World Vision Myanmar. Leading to the livelihood opportunities, providing agriculture training such as SALT method and provided good quality of seeds, animal husbandry training such as providing limited number of pigs, hens, ducks, fish species etc., and for representative of fish pond owners, vulnerable people by Department of Agriculture, Department of Animal Husbandry and Veterinary organized by Non-Government Organization.

CHAPTER V
CONCLUSION

As a Public Health Problem in 2003, the National Leprosy Programme in Myanmar achieved the global of Elimination although, the fight against leprosy is still not over as yet for the National Leprosy Control Programme, and its efforts must be maintained till the country is finally free from this disease. About 10 to 15 per cent of new leprosy patients suffer physical disabilities is shown by an official of the Ministry of Health and Sports. The new cases of leprosy are found 0.45% (per 10,000) in the whole Myanmar. It is required to prevent, reduce discrimination and support social-economy because of being new leprosy patients in Myanmar. The Myanmar International Convention Center II, held the National Leprosy Conference in Naypyidaw in December 31, 2018. So, National Leprosy Control Strategy (2019-2023).

5.1 Findings

This study focuses on social-economic conditions of leprosy-affected people who are facing barriers, challenges and to access health, education, economic, social communication and employment opportunities. In this study, leprosy-affected people inclusion in health sector, barriers and challenges of person with disabilities in access to healthcare services, employment opportunities and vocational training are examined based on their responses to the questionnaires and face to face interviews with Leprosy people and their families, village head, Sister of Charity, leprosy campaign of Keng Tung Hospital. And this study addresses the gap through an international review of the literature, surveys, and interviews.

Leprosy patients and their family who is in Naung Kan village are doing 38.6% growing shifting cultivation, 5.2% of growing paddy field,2 % of growing gardening, 3.4% of doing home gardening and 50.8% of others like vendors, construction workers, daily workers, dependents, government staffs, company staffs, and small merchants. Simple Random Sampling method and the key findings of the survey data shows that their incomes. The lowest income of people is 150,000

(56.10%) and the highest income of a few people is above 300,000 (2.44%). The middle range is between above 150,000 to 250,000(18.70%) and 250,000 to 300,000 (11.38%). The lowest expenditure of people is 150,000 (52%) and the highest expenditure of a few people is above 300,000(3.3%). The middle range is between above 150,000 to 250,000(21.1%) and 250,000 to 300,000 (13%). Finding no balance in their income and expenditure because of social issues, business crises, charges of leprosy treatment and other health issues. As livelihood conditions, small brokers and merchants are collected the paddy, seasonal fruits and vegetables such as pennants, corns, mustard, and pineapple are selling in Mong Lar township (border area of China) and Tachileik (border area of Thailand). Naung Kan Leprosy Colony is one of the factors of the economic zone and stayed on the Loi Mwe village. According to the Government plan of the next come years, Loi Mwe township will come to develop of economic zone and there are connecting to Tachileik (border area of Thailand). According to the main finding, 48.76% of respondents people who suffer leprosy disease that control the leprosy disease in this Naung Kan Leprosy Colony. As a discussion, five new leprosy patients found per year last 10years ago. Currently, only one new leprosy patient found per five years. According to the discussion of Leprosy Campaign Leader of Keng Tung Hospital, migrant workers (Central of Myanmar) and mountain regions have occurred leprosy diseases. From his experience, leprosy disease also can occur even in three months infants to ninety-five ages. Among the fifty-nine patients, 59.3% of leprosy people who are completed and 40.7% of leprosy patient who are uncompleted. There are fifty-nine leprosy patients who take treatment from the leprosy colony and health care center. Leprosy patients took 3months, 6months, one year and three years of treatment depend on their health conditions. According to the policy from leprosy colony, leprosy patients and their families obeyed rules and regulations so that they can reduce patients, prevent and controlling disease until their generations. Leprosy patients who completed or not and their families are staying in Leprosy Colony village giving human rights by Father Colombo. Besides, there was a nursery school and middle school in Naung Kan Village where the children learn from leprosy colony and around it. Another finding is the fifty-nine-leprosy people from one hundred and twenty-three households can participate village's activities are 97.56% and 2.43% cannot have participants for a bad stage of leprosy disease. 93.49% can do decision making in meeting. 77.23% have discrimination in the social relationship but 22.76% have discrimination in the

social relationship and banish them from their native village last early 20 decades. 98.37% of the leprosy family members can get job opportunities by applying government office, company, and other business sectors. The government side gave the leprosy patients regular medical checkups, prevention and treatment, free charges of hospital, artificial legs and a pair of crushes, supporting school building, village road, drinking water tank, village development support for revolving fund. Accessing awareness of health care service, prevention of HIV/AIDs, TB, Malaria project, mother and child awareness training, education awareness, revolving funds, livelihood training and material supporting by the role of INGO/NGO. Another finding from this study, both government and INGO/ NGO are providing long term health care service (treatment and prevention), village development program that can reduce stigma and help to get human rights including social activities in their atmospheres.

5.2 Suggestions

The survey found that having caregiver of Sister of Charity and medical treatment in time are the strongest points of Leprosy Colony in Keng Tung. Allowance by policy of leprosy colony home, leprosy people and their families who are asked to leave from their native village had settled in this place. The wiliness to work by themselves in livelihood. By reviewing livelihood sectors the three main roles, agriculture, animal husbandry and other sectors, government, non-government support for this three-main role that are good points. Among these good points, better technique and material support for these three main roles should be provided as the government and non-government that can reduce unbalancing income. A good transportation is one of the business opportunity and it can be communicated to other villages and townships. And also, there have many human resources, small lands can be growing such as soybean, pennants, peppers and feeding animals and other jobs. Another good point is that the children can learn easily about education not only in the village but also in other schools or universities. Vocational training plans should be provided for 34% of drop out students. In terms of knowledge and practice of the Rights of Persons with Disability Law (2015), it is important to advocate because the leprosy (disability), health awareness campaign became all-inclusive in their life. Examining the whole survey, socio-economic status and livelihood opportunities accessible of people affected by Leprosy are better than the previous age.

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APPENDIX A
Questions for Focus Group Discussion
Socio Economic conditions of Leprosy affected people in Naung Kan Village, Keng Tung Township.

Please tell me about the Naung Kan Leprosy Colony history?

- How many people are suffering from leprosy disease? Who are they? Where are they come from and leprosy disease control in this village?
- Who is suffering from leprosy disease are systematically cured by the treatment in hospitals, missionary, and other donors.

Please describe the livelihood condition?

- What is their occupation? Who are accessible for the educational condition of Leprosy people and their families?
- Have you or your families suffered social discrimination of leprosy disease?
- Do you have any scholarship program in school if there is a person who suffers leprosy disease in you and your family?
- Any problem or challenges about the education conditions for Leprosy people?

Please tell about the socio-economic situation?

- Could Leprosy people participate in the activities in the village? Any reasons?
- Could Leprosy people decide the activities or meeting of the village? Any reasons?
- Do you have any discrimination due to the family members who suffer from leprosy disease?
- Will there be any job opportunity if the person suffers from leprosy disease in their circumstances?
- What is the livelihood opportunity and challenges?

What is the supporting for other factors in this village?

- What kind of support of health care service, education service, and social development activities from government, non-government and other donors?
- Currently, how much efficiencies and effectiveness of this supporting? And, do we need to do more? What else? Do you have any suggestion to improve this area?

APPENDIX B

Survey Questionnaire

Socio Economic conditions of Leprosy affected people in Naung Kan Village, Keng Tung Township

Household number ( )ı Household head ----------

Age ( )years, M ( ), F ( )

Interviewer ……. Signature…….

Supervisor……. Signature……

Naung Kan Leprosy Colony, Keng Tung

Date……ı……ı 2019

Socio-Economic Demographic Characteristics

1.1 Demographic Information

(A) Family relations with interviewee ……..……

(B) Marital status ……..

(C) Family members Total ( ), M ( ), F ( )

(D) Religious

1	Buddha	
2	Christian	
3	Hindu	
4	Muslim	
5	Others(specify)	

1.2 Livelihood Conditions

It is collected about their livelihood conditions in their village.

1.2.1 Agriculture

1	shifting cultivation	
2	Paddy field	
3	Gardening	
4	Home gardening	
5	Others(specify)	

1.2.2 Animal Husbandry

1	Poultry/Ducks	
2	Pig	
3	Buffalo/Cow	
4	Fish pond	
5	Others(specify)	

1.2.3 Others Job

1	Construction worker	
2	Daily worker	
3	Handicraft worker	
4	Beggar	
5	Others(specify)	

This question means how to survive in family with their income and expenditure.

1.3 Family Income

1	<150,000	
2	150,000 - 250,000	
3	250,000 - 300,000	
4	Above 300,000	
5	Others(specify)	

1.4 Family Expenditure

1	<150,000	
2	150,000 - 250,000	
3	250,000 - 300,000	
4	Above 300,000	
5	Others(specify)	

The reasons why family income and expenditure not balancing are as follow;

1	Health	
2	Education	
3	Social Activites	
4	Economics	
5	Others(specify)	

1.5 Transportation and communication

The Conditions of Healthiness in the village

In this part, leprosy patients/ the person who suffered leprosy or one of the family members who is suffering from leprosy disease are systematically cured by the treatment in hospitals, missionaries, and other donors.

2.1 self ( ) or families ( )

(A) Suffering from leprosy disease(date, months, years) ……

(B) Medical treatment for leprosy disease(date, months, years) ……

(C) Leprosy disease are recovery/ completed(date, month, years) ……

2.2 Leprosy disease curing are as follow;

1	Treatment from hospital	
2	Traditional method	
3	Leprosy colony	
4	Self-treatments	
5	Others(specify)	

2.3 Any problem or challenges when the leprosy people taking medical treatment or service?

……

……

The Conditions of Social Issue in the village

3.1 Could Leprosy people participate in the activities in the village?

can ☐ cannot ☐

If not have, the reasons were

……..……

……..

3.2 Could Leprosy people decide the activities or meetings of the village?

can ☐ cannot ☐

If not, the reason are

……..……

……..…….

3.3 Do you have any discrimination due to the family members who suffer from leprosy disease?

1. yes, I do ☐ 2. No, I don't ☐

3.4 Will there be any job opportunity if the person suffers from leprosy disease in their circumstances?

1. yes, there will ☐ 2. No, there won't ☐

3.5 Do you have any supporting and services in village if there is a person who suffers leprosy disease in you and your family?

1. have ☐ 2. not have ☐

Support and Service of the Government and Non-Government Organizations
(Y = Yes, N = No, DK = Don't Know)

Support and Service	Government			NGO		
	Y	N	DK	Y	N	DK
(A) Health Service • Leprosy campaign and awareness • Leprosy treatment • Material support for leprosy • Family planning • Others						
(B) Education Service • Material support for children • ECCD campaign and awareness • Scholarship program • Supporting building • Others						
(C) Village Development Service • Awareness of rural development • Supporting for drinking tank, well • Supporting latrine • Supporting for Village road or bridge • Others						