

# Final Report of Work Camp in Indonesia 2015

## 1. Leprosy Care Community University of Indonesia

Leprosy Care Community University of Indonesia (LCC UI) has organized Work Camp in leprosy recovered colony in Indonesia since 2010. We have organized Work Camp with big scale of work project only in Nganget leprosy recovered colony in East Java from 2010. Work Camp in Nganget leprosy recovered colony is known as unique activity for persons affected by leprosy among university students in Indonesia for this 5 years. In 2015 we start organizing Work Camp in 1 more leprosy recovered colony, Donorojo leprosy recovered colony in Central Java. Increasing number of volunteers from several universities in Indonesia, from University of Indonesia, Diponegoro University, or Airlangga University, is the reason of organizing Work Camp not only in Nganget leprosy recovered colony but also in Donorojo leprosy recovered colony this year. A volunteer has interaction with person affected by leprosy, builds close relationship while Work Camp, and shares experience to society for decreasing discrimination and stigma against leprosy and persons affected by leprosy. We are glad that more volunteers had interaction with more persons affected by leprosy not only in Nganget leprosy recovered colony but also in Donorojo leprosy recovered colony this year. And we would like to express our deepest appreciation for your help and support to our projects.

## 2. Nganget leprosy recovered village

### 2.1 Information of Nganget leprosy recovered village

Nganget village is located in Tuban, East Java. It is around 20 km from north of Bojonegoro and it takes around an hour to go there by bus from Rajekwesi Bus Station in Bojonegoro. It is geographically far from society as it is surrounded by hills and forests. It is almost remote area.

Historically, Nganget village was built by the colonial government of Netherlands as leprosy

colony in 1935. Since 1947 – 1985, it was handled by Rumah Sakit Kusta Nganget Tuban (a leprosy hospital). Since then, a Social Unit from government of East Java Province has taken over and held a rehabilitation house for people affected by leprosy. Data from the Social Unit shows that there are 175 families live in Nganget village and around 85 families of them are people who were affected by leprosy.

The name of 'Nganget' village, which literally mean warm, was taken from its natural hot spring. The hot water arises from natural spring and flows in the middle of river which splits the village into two areas. In the past, only the local villagers used the hot spring for warming their body. Now, it becomes well-known and a lot of people from outside the village visit there regularly.

Villagers who live in Nganget village have various jobs. As the Social Unit has a large land for plantation, most of them are farmer and trader who are worked for Social Unit. Some villagers depend on forest resources such as woodcutter, carpenter, and craftsman. Besides of it, many of them have a job as civil servant of the local government. However, for some villagers, they have no choice for job except become unemployed due to their disabilities. As discrimination against people affected by leprosy still exists, their daily life faces many problems in psychosocial, economic, and infrastructure. In psychosocial problem, they have lower self-esteem and it causes them become isolated from social, especially from people outside Nganget. Another thing to point out is that even though they have various jobs, the discrimination affects negatively on their economic, especially on certain job like traders. They are difficult to sell their goods because people outside Nganget are afraid to buy something from them. Because of that, their goods are only bought by villagers from Nganget and it causes a decrease in their income. Another problem is found in their infrastructure within the village. Because of isolated community from society, there is no service from society or government for improving their infrastructure.

## 2.2 Work Project

### A. Repairing hot spring

There is a hot spring bath in the center of Nganget. It had existed since Netherlands colonialism. There are two rooms in the bath, one is high and another is middle temperature of water. Besides this bath hot water arises in river, however villagers especially elderly persons prefer to use the bath because water temperature in river is not stable and it can cause scald unconsciously. It is said that the hot water in this hot spring bath can soften pain in body. There are several sections that should be repaired to make the hot spring bath more comfortable to use.



1. Inside of bath is filled by water plant. It makes floor dirty and slippery.
2. There is no wall or door in entrance, so inside can be seen from outside.
3. Bath floor are already broken. It makes

4. Dirt path to the entrance is unpaved. Wall is almost broken.



Villagers and campers worked together to clean areas near the bath, we removed grass, thrash, and cleaned inside the bath to make it easier to do some repair. The hot spring flow also had to be directed to another place so the hot spring bath could be empty and easy to clean.



Put ceramic tile on inside of bath. Many professionals from villagers helped us to do this work. We installed the ceramics at noon and night. Villagers who have their own job at noon helped our project at night time.



For making people outside would not see people inside the bath, we built two walls in front of the entrance to block the eyesight from outside. After cleaning the area, we built walls 3m x 1.5m.



Cracked areas were patched by cement and steps into the bath also repaired.



We removed cracked bricks on the wall and covered with cement as new wall surface.

And we repaired steps and path to the bath. This covered road would help people will not get dirty again after bathing. The road shouldn't be slippery so we made the road a little rough.

Before Project

After Project





## B. Repairing Shower Room

In Nganget, there is also a public shower room which flows the hot spring. Villagers use the shower room to take a bath, or sometimes to washing clothes. However, this facility also must be repaired because there are some damage and uncomfortable for using.



1. Shower room.
2. Broken roof of the shower room.
3. Shower room has low ceiling.
4. Broken and dirty floor.



First we removed the roof and cleaned areas near the shower room. After that we put bricks for making additional wall for high ceiling. After that we installed new roof on the top. The broken parts of floor and the building were patched by using cement. We made the floor quite rough so people who take a bath will not feel slippery. At last, we installed the LED lamp in order to make the shower room could be used at night.

Before Project



After Project







### C. Road Project Details

LCC's campers, who hold Work Camp in Nganget in 2010, repaired main road in Nganget as project. It was the first Work Camp that was held in Nganget. Villagers and campers worked together for the first time during road project in 2010. The road has been used by villagers until now even though there were damages and cracked part in that road by 5 years use. After Work Camp in 2010, there were some organization who proposed to repair that road again, but villagers rejected their proposal and keep the road as it was. Villagers said that the road is precious memory for us. Even poor condition, it should not be repaired because once repaired by asphalt, our memory cannot be seen anymore. A member who joined Work Camp in Nganget in 2010 heard the story and proposed to villagers to repair the

road again by ourselves. After discussion with members joined Work Camp in 2010, LCC, and villagers, we decided that we repair the road again and the fund for the project supported by members who joined Work Camp in 2010.



The reparation was done by campers and villagers. The stake holders in Nganget divide villagers into few shifts and few work parts. There were one neighborhood association (we called it 'Rukun Tetangga' or RT) who were responsible for the road project each day. The reparation was usually started at evening or night because the villagers have to work for living in morning and afternoon. We surprised because there were so many villagers who came to help. They gathered at evening and work hand in hand together. When we were working, villagers, especially women, brought many foods for us and they talked a lot to us about the Work Camp in 2010, how they surprised when university students came for the first time and worked for them, and how they surprised because they never refuse interacting with persons affected by leprosy.

For a few days, the road was closed for public use because it needed time to completely dry until it can be used. Every day, there were villagers who splashed water on the road so the shrinkage of the material will be faster. We felt more close with campers who joined Work Camp in 2010, because this project reminds us with our seniors and it also shows that work

camp mission which were brought in 2010 were still same with work camp mission that we bring in this year.

Before Project



After Project



### 2.3 Publication Project

We hold publication activity to people who live around Nganget leprosy recovered colony for knowing how much knowledge they have about leprosy and how they feel about leprosy and persons affected by leprosy in Nganget. For the first year in 2010, motorbike taxi driver refused to taking us to Nganget. Or passengers in public bus ignored us when the passengers knew that we go to Nganget. LCC has already organized Work Camp in Nganget for 6 years from 2010. So this publication activity was planned for knowing what could be changed for this 6 years.

We interviewed 38 persons who live in regions outside Nganget. Most of the interviewee live in Kedung Jambe village, a village that locate nearest with Nganget, but we also interviewed persons that we met in shops, Singgahan market, and Bojonegoro city. We made a questionnaire for the interview. In the questionnaire, except the demographic data of interviewee, we must ask four questions to him/her. The response of the questions is consisted of dichotomous response (yes/no) and descriptive response. Below are the questions that we asked;

1. Do you know about leprosy? If yes, descriptions about leprosy?

2. Do you know about Nganget leprosy recovered colony? If yes, descriptions about persons who live in Nganget?
3. Do you know about our work camp? What is your opinions about the activity?
4. Do you want to come to Nganget to join some activities?

For question 1, among 38 persons, 29 of them answered that they know about leprosy, but their descriptive answers were varied. Some of them already had a right information about leprosy, such as leprosy can be cured, the signs of leprosy on body, etc. But some think that leprosy can be spread in night, through sweat and leprosy can be affected to person who has same blood type. From 29 persons who answered that they know about leprosy, 9 persons had wrong understanding about leprosy or they could not describe what is leprosy. Among 9 persons who answered that they don't know about leprosy, some said that who affected by leprosy is because he commits a sin. Most of interviewees who had right information about leprosy said that they got it from their experience in socialize with persons affected by leprosy. From this result we found that over 75% persons know about leprosy, however, only 52% have right knowledge about leprosy.

For question 2, among 38 interviewees, 35 of them answered that they know about Nganget village. Some of interviewees said that they have been to Nganget occasionally to work, socialized, go to hot spring, etc. There are also some interviewees who said that their acquaintances (husband, parents, siblings, etc) live in Nganget now or lived in Nganget in the past. Most of them don't have problem to socialize with Nganget villagers.

From question 1 to 2, we found that people in society, the nearest community from Nganget, know about leprosy and Nganget including the case that their acquaintances have ever lived or now live in Nganget. It means persons affected by leprosy have been accepted in society, the nearest community, with daily interaction. However, 48% in society have wrong knowledge about leprosy. The spread of correct information about leprosy is important for more active interaction between people in society and in Nganget. We found quite positive attitude about leprosy in persons in the nearest community from Nganget, however, on the

other hand we could not reach to people in society, who haven't interacted with people in Nganget. The question how people who live little bit far from Nganget and haven't interacted with people in Nganget think about leprosy still remains.

For question 3, among 38 interviewees, 35 of them answered that they know about our activities in Nganget organized by university students. Most of them said that our activities have a positive effect for Nganget, such as it makes many villagers outside Nganget came to Nganget because they know there are events that held by students there and it made Nganget facilities much better than in the past before we came.

### **3. Donorojo leprosy recovered colony**

#### **3.1 Information of Donorojo leprosy recovered colony**

Donorojo leprosy recovered colony is located in Jepara, Central Java, Indonesia. The name of "Donorojo" means Dono (Gift), and Rojo (King or Queen). Queen Wilhelmina, Queen of the Kingdom of the Netherlands built leprosy hospital and church in this place for leprosy patients all over the Dutch East Indies.

In Donorojo, there are around 60 people in "Liposos (Lingkungan Pondok Sosial)", social houses and around 800 people in Rehabilitation village. Persons affected by leprosy in Liposos get support from local government such as houses, rice, and money. On the other hand, who live in Rehabilitation village make their own living by themselves by having job such as farmer, trader or carpenter. They feel difficult to manage their money because they have no market to sell their wares. They still face so many problems such as people from outside afraid to buy something from villagers because it made by persons affected by leprosy. The other problem is about infrastructure, the villagers have given houses by the government but the condition was poor, some of them need to be repaired as soon as possible. The other poor facility is the road in leprosy recovered colony, the asphalt was broken and need to repair soon.

### 3.2 Project Details

Persons affected by leprosy in Liposos live in houses that are provided by local government. However, condition of those houses are poor because of long time use.



1. Embankment for houses are broken because of heavy rain.
2. In rainy reason, water will flood and come into road, and houses area.



Measure the dike to be built and aligned using threads and gauges. Put big stones along with aligned line, then fix the embankment by using cement. This project need technical skill but with cooperation from villagers, who always do construction work, we could finish making embankment with length 24 m.

Most of people in Liposos don't have toilet facility in their own houses. They use public toilet in the Liposos, however, road access to the public toilet is not covered. In the rainy season the road is filled with rain water and difficult to use.



1. 2. Access to the public toilet. Unpaved and rocky.



Measuring the land about 60 meters by using threads to make it straight and neat. Put bricks along the measured line, then put soil as same height as the bricks.



Put paving blocks on the road. This road will be higher than other land area, so the road will not be covered with water even in rainy season.

Before Project



After Project





### 3.3 Publication Activity

For organizing Work Camp in Donorojo leprosy recovered colony, it is important for us to know surrounded condition about leprosy. We prepared questionnaire and interview people in society near Donorojo leprosy recovered colony.

The response of the questions is consisted of dichotomous response (yes/no) and descriptive response. Below are the questions that we asked;

1. Do you know about leprosy? If yes, descriptions about leprosy?
2. Do you know about Donorojo leprosy recovered colony? If yes, descriptions about persons who live in Donorojo?
3. Do you know about our work camp? What is your opinions about the activity?
4. Do you want to come to Donorojo to join some activities?

We interviewed people around Donorojo and in market area. While this project, we could collect 61 answers.

From 61 interviewees, 44 people answered that they know about leprosy, and 17 people answered they don't. However, among 44 people some answered that leprosy cannot be cured, can be affected by sharing food, can be affected through sweat etc. And most of them said that who affected by leprosy lose their fingers. It seems that basic information about leprosy, leprosy can be cured, and aftereffects can be prevented by early treatment, are not known generally in the society. Here we must note that among 61 interviewees, 12 interviewees use the words "dangerous", "fear", or "dirty" for explanation of leprosy.

For question number 2, we also asked about the existence of leprosy colony, especially Liposos and Rehabilitation Village there, 21 interviewees answered they know and 40 answered they don't. It means that only 1/3 know the existence of leprosy recovered colony.

For question number 3, 48 people answered yes, it should be there more socialization about leprosy because they were feeling curious about it. But for 13 people answered no, it should not be there more socialization about leprosy because they do not want to interact and felling afraid with people affected by leprosy. More than that, we also doing socialization to

our respondent to give them more understand about leprosy. We used flyer that contain what is leprosy as media and we had given it to the respondents. After we explained, there are still about 9 people that still doubting the safety to interact with people affected by leprosy, 7 people still need ensured by their own experience, and others admit that interact with people affected by leprosy is safe and want to try to interact with people in Donorojo. But, some respondent also there still refuse to go near rehabilitation village.

Other than that, we also told them about our agendas in Jepara Work Camp 4<sup>th</sup> and our aim to decrease the discrimination on the people with leprosy. This is also explained for the question number 4 and 22 people answered want to join our agendas, 18 people still rethinks, while 21 people refuse because of their business and activities. To spread the knowledge of leprosy and rehabilitation village about decreasing the discrimination, 48 people said that they will told their colleagues and families not to discriminate people with leprosy and taking a picture to be uploaded to the social media as a campaign to decrease the discrimination, while 13 people refuses to do the same.

#### **4. Publication Project after Work Camp**

Volunteers who joined Work Camp and had interaction with persons affected by leprosy built close relationship with persons affected by leprosy while Work Camp. They felt villagers' characteristics and personalities by direct interaction with persons affected by leprosy. Who joined Work Camp will never have discrimination against leprosy and persons affected by leprosy. However, only few university students could join Work Camp. Most of people in society haven't been interacted with persons affected by leprosy. And many of people in society still have discrimination or stigma against leprosy or persons affected by leprosy. To let them know more about leprosy and persons affected by leprosy, we hold photo exhibition for sharing our experience while Work Camp. We hold photo exhibition at 3 cities in Indonesia, Depok, Semarang and Surabaya. Each photo exhibitions were handled by local university students who joined Work Camp this year, Depok by students from University of Indonesia, Semarang by students from Diponegoro University, and Surabaya

by students from Airlangga University. We asked some questions to participants who came to the exhibition.

Question 1. Can leprosy be cured?

Question 2. Can medical treatment for leprosy be accessed for free?

Question 3. Are persons affected by leprosy and their family members still discriminated?

We asked those questions before and after participants see photo exhibitions about leprosy. While the publication project (Depok 2-4 November, Semarang 1 and 4 November, Surabaya 7-8 November), we collect answers to our question from 210 persons.

For 1<sup>st</sup> question, 160 persons answered “yes” and 50 persons answered “no”. After they looked our exhibition about leprosy information, we asked same question. Finally, 204 persons answered that leprosy can be cured. For decreasing discrimination against leprosy, it is the first step for people in society to have right knowledge about leprosy. In this point, we could gain new 44 persons who know right knowledge about leprosy by this project.

For 2<sup>nd</sup> question, Indonesian government prepared medicine for leprosy in “Puskesmas (Pusat Kesehatan Masyarakat)”, Community Health Center, and medicine can be accessed for free. However only 68 persons from 210 persons know about the fact and 142 persons don't. Leprosy can be cured, and patients can get medicine for free. This information is important for early treatment. By early treatment, leprosy can be cured without having aftereffects. For this question, we found big change before and after looking our exhibition. The number of persons who know about the fact increased from 68 to 192 by knowing the fact from exhibition.

At last, we asked 3<sup>rd</sup> question, “Are persons affected by leprosy and their family members still discriminated?”. 146 persons answered “yes”, and 64 persons answered “no”. The purpose of this question is not giving image of “pity” about persons affected by leprosy. Our purpose is sharing our experience with persons affected by leprosy while Work Camp. While Work Camp, villagers in leprosy recovered colonies supported our project by working together, and sharing their food for us. And we learnt power to live in difficult condition. By

sharing those experiences, we targeted to not giving stereotypical image about persons affected by leprosy but telling various, and unique characteristic of them. We asked 210 persons to describe their opinion about the answer of 3<sup>rd</sup> question after looking our exhibition. They gave their opinions that “Persons affected by leprosy should not be discriminated”, “This is the first time to know about persons affected by leprosy. LCC should hold larger scale of this exhibition so more people know about leprosy”, “It was very valuable because I could see their lives” etc.



Show information about leprosy.

1. Leprosy can be cured.
2. Free for medicine.
3. Persons affected by leprosy and their family members should not be discriminated.



Guide visitors in the exhibition.

Show information about leprosy, pictures while Work Camp.

Visitors answered our question sheet before and after seeing exhibition.



#### 4. Evaluation of Projects

For all Work Project both in Nganget and Donorojo leprosy recovered colonies, we could complete the target within scheduled duration and budget. While the project, we could get much support from villagers. Some villagers said that before meeting with us persons affected by leprosy often stay all day long in their houses because they afraid to meet others. However, they gradually started to open their mind to others with interaction with university students who worked for them.

Work project were decided after needs assessment survey and discussion with stakeholders. So we could involve many villagers to join the construction project. It also contributes to sustainability. Because they joined construction project and it is necessity facilities for them, they will maintain and keep the facilities with good condition. By improving public facilities in leprosy recovered colony, people living around the colony started to come to the place, especially in Nganget leprosy recovered colony. By work project, we could remove negative images such as “dirty” or “dark” about leprosy recovered colony in society.

On the other hand, for publication project, we found some problems. Because our interview target is not decided in detail, it was difficult for us to analyze the result data. For example, many of interviewees in Ngagnet had ever interacted with persons affected by leprosy. So it was difficult to know how people in society think about leprosy. If most of persons in society have experience to interact with persons affected by leprosy, we should

find out that where is the boundary of people who had ever interact with persons affected by leprosy and not. We should improve our interview survey method more in next time. For example, hold interview survey to people in society in some areas, nearest community from leprosy recovered colony, community it has distance from leprosy recovered colony. And we should consider the transportation access to the community and leprosy recovered colony. Whether there are any relationships between discrimination and transportation access to leprosy recovered colony, it should be found out clearly to know the exact attitude against leprosy and persons affected by leprosy.

For publication project in some universities, we could collect enough result. Not only giving information about leprosy, but also sharing experiences of communication with persons affected by leprosy while Work Camp, many of visitors get interest in their lives. We think that it is important for decreasing discrimination against leprosy by organizing photo exhibitions after Work Camp to share our experience to much more persons.

This year we could finish all project in leprosy recovered colonies in Indonesia. We surely believe that we could decrease discrimination against leprosy and persons affected by leprosy this year through the projects. We would like to express our deepest appreciation for your help and support for the projects. In Indonesia, there are still many leprosy recovered colonies and persons affected by leprosy who are in difficulties because of discrimination or stigma to them. We will continue our activities with our best effort for making the world without discriminations against leprosy and persons affected by leprosy.

## 5. Accounting Report

Project fee for Nganget and Donorojo leprosy recovered colonies

Income	Amount (IDR)	Expense	Amount (IDR)
Sasakawa Memorial Health Foundation	IDR 15,357,000.00	Work Project in Nganget	IDR 5,985,000.00
		Work Project in Donorojo	IDR 8,041,000.00
		Publication Project	IDR 1,428,000.00
Total	IDR 15,357,000.00	Total	IDR 15,454,000.00
Balance (Income - Expense)*			IDR -97,000.00

\*Balance amount IDR -97,000 covered by camp fee.

Road Repair Project in Nganget leprosy recovered colony

Income	Amount (IDR)	Expense	Amount (IDR)
Mr. Miyoji Morimoto	JPY 30,000.00	Road Repair Project	IDR 4,533,500.00
Ms. Yukako Sakiyama	JPY 1,000.00		
Ms. Shoko Hirai	JPY 5,000.00		
Mr. Daichi Takabatake	JPY 5,000.00		
Ms. Marie Sakakura	JPY 1,000.00		
Ms. Nurul Azmi	IDR 50,000.00		
Mr. Affan Nurrohman Wiguna	IDR 100,000.00		
Ms. Erni Astutik	IDR 100,000.00		
Ms. Tika Dwi Tama	IDR 200,000.00		
Ms. Luriana Nur Pratiwi	IDR 100,000.00		
Takashima Yuta	IDR 200,000.00		
Total*	IDR 5,118,000.00	Total	IDR 4,533,500.00
Balance (Income - Expense)**			IDR 584,500.00

\*JPY were exchanged into IDR with rate 1 JPY=104 IDR.

\*\*Balance amount IDR 584,500 will be used for work project in Nganget for 2016.