

Report of Work Camp in Nganget Leprosy Recovered Colony in Indonesia 2017

Background

Leprosy Care Community (LCC) has organized Work Camp in Nganget leprosy recovered colony in Kedungjambe, Tuban, East Java, Indonesia (photo 1) since 2010. LCC has developed villagers', especially persons affected by leprosy, living environment by improving infrastructure such as paving main road, building public toilet, making drainage, or repairing floor for public hot bath, etc. By 7 years' continuous projects, their living environment has been improved substantially by 2016.

Improved living infrastructure and an annual visiting by university students from Japan and Indonesia have attracted people, who live near the colony, in Nganget and they have started to come to Nganget and interact with villagers.

In these condition, it is the next challenge for villagers to built independent community that is not rely on support from outside, and to live by helping each other under the condition that many of persons affected by leprosy is getting old and the young work and live outside of Nganget.

Vision of the Future, and Deciding Work Project

For holding Work Camp in 2017, we set meeting with some representatives of the colony for discussing about work project. The colony is divided into 3 areas, called RT, namely RT 3, RT 4 and RT 5. Representatives from each RT and "Kali Panas Team" which is youth community organized by some youth in the colony. Kali Panas Team had organized for the vision that is to provide change and reach the common goal, which is to be more advanced, friendly, beautiful and dignified village. Routine activities undertaken by the youth community is like social gathering, mutual cooperation, community service and taking care the facilities in the Nganget village.

What we focused while the discussion is whether LCC holds project for improving living infrastructure or hold project that helps villagers to improve their living infrastructure by their own hands. Some villagers, including Kali Panas Team already started to consider their and thier village's future. So, it will be the best way for them to develop the village on their hands in the future. However, there are still some problems they face for continueing their community development, such as money for improving or repairing facilities in the village, or other villagers' opinion like "we cannot do anything" comes because of self-stigma and low self-esteem. So, we targetted for developping independent community by villagers' own hands as long-term goal, and for giving solution for getting income for the village and decreasing self-stigma as short-term goal.

Mr. Purnomo and Mr. Nathan, founders of Kali Panas Team argued that the thing that needs to be built is the footpath from the car park to the hot water river and a changing room for hot water visitors. The two proposals are focused on facilitating visitors to Nganget hot springs. Many residents outside of Nganget come and visit, either for just bathing, bathing or recreation because of the hot springs. The hot springs become the object of the visit that is very interested by the residents outside/ around Nganget. However, before the project is implemented, there is no adequate facilities in the hot springs, which makes visitors feel less comfortable. If you want to go to the hot springs, the visitors have to pass through the difficult road for people with disabilities. In addition, the increasing number of visitors made the existing dressing room facilities become less and required the construction of a new dressing room to facilitate the visitors of the hot springs. They consider that the hot springs as object of visitation can be used as a medium to reach one of their goals, which makes the village advanced and independent. They explain that when the hot springs at Nganget have adequate facilities and comfort for visitors, the visitor numbers can increase gradually. In the future, a voluntary contribution box will be placed, and the money contribution will be entered into the treasury of Kali Panas Team, which in the future can be used to maintain and take care of existing facilities in Nganget, and help the people who need assistance, such as medical expenses or transportation cost to hospital, etc.



Meeting with representative of villagers



Hot spring in the village in 2016

At result of the meeting, LCC and villagers decided to build a footpath facility and changing room around the hot springs. On the basis of these considerations, LCC wants to support the movement and ideals of youth community, Kali Panas Team in Nganget to make the village become advanced and independent. It is expected that with the construction of the facility, the number of visitors of hot springs coming from outside Nganget will increase. By increasing number of visitors from outside of Nganget, interaction between outsiders and Nganget villagers who affected by leprosy expected to be increased and the interaction will change the mindset of people live outside of Nganget and eliminate the stigma that has been attached to Nganget and also help removing self-stigma of villagers themselves.



Conceptual drawing of the project

Team Building for Volunteers

For organizing the project, we recruited 18 Indonesian students and 11 Japanese students. We provided training about leprosy, work camp and the reason and concept of work project of this year. By the training, they understood the importance and the meaning of the project, that is, important is not only finishing the project but also the process which volunteers work together with villagers to raise their awareness for their own village for their community development.

Work Project

While implementation of the project, we expected that villagers join project proactively and independently for getting first experience for community development by themselves, which was targeted as long-term goal.

During the progress, volunteers accompanied by one handyman and one assistant. And villagers and the youth also working together called 'kerja bakti'.



“Kerja bakti”, working together with villagers



Making Road to Hot Spring



Building Changing Room

This year, we changed the concept of work project from project that improves living infrastructure for villagers to project that helps community development. So, we and villagers raise a monument with expectation that this road and changing room become the first step for developing independent community. On the monument, information about leprosy and history of Nganget were wrote for people who use the road and changing room getting understanding about leprosy and this village. we are hoping that outsiders who visit Nganget can open their minds and perceptions about leprosy and people who affected by leprosy.



Road to Hot Spring



Changing Room

Home Visit

Besides work the other main activity in the workcamp was called home visit. Home visit was an activity to visit villagers' houses. Volunteers are free to do Home Visit. When Home Visit, volunteers interact deeply with the villager, not only chatting and telling stories, volunteers also follow their daily routine, for example helping them work in the fields. With more personal interaction and close relationships between villagers and volunteers, it is hoped that the villagers will be more open, confident, so that they can reduce their self-stigma.



Interaction with villagers

Youth Sharing

Youth sharing is a brand-new program that we held in 2017. The background of the program was to motivate the young in Nganget to build an independent community in the future. This program is the first step in the change of NIWC's focus from building facilities to community development. The activities are gathering between volunteers and the Kali Panas Team. Some volunteers then express the reason why they came to Nganget and his impressions towards Nganget. Volunteer expresses feelings in deep thinking with hope after knowing our reason to Nganget, Kali Panas Team can understand the purpose of us, as well as introduction so it will be easier to assist them. This event is a pilot project, which in the future we will developed it again to adjust social situation and community in Nganget.



Sharing by volunteers



Sharing by Kali Panas Team

Evaluation of work project

For evaluating work project, we monitored effectiveness after work camp, and result of monitoring reported by Mr. Purnomo, the representative of Kali Panas Team. Report said that the concept of the project this year was totally understood by all villagers so they never disappointed even though the project is targeted to not villagers in Nganget but for people in the society. They have positive response toward the project because stigma or discrimination toward Nganget or persons affected by leprosy started to decrease by increasing number of visitors from outside. After building road and changing room, more visitors come than before, and hot spring is full of visitors every day. People who use the changing room donate their money, even not so much amount until now, and the money is used for cleaning changing room or social activity held by Kali Panas Team for Nganget.



Cleaning village



Maintain the road built by the project

Exhibition

As the closing activity of the workcamp project on this year, we held an exhibition titled “LCC Photo Exhibition 2017: *Asa dalam Lara* (A Hope in a Sorrow)”. This exhibition was held in Central Library of university of Indonesia, on November 13th – 15th 2017. This title was chosen to show the society the stories behind the struggles of villagers in Nganget. *Asa* (A Hope), are positive things, hopes, and dreams. While *Lara* (Sorrow), describes sadness and painful moments. *Asa dalam Lara* (A Hope in a Sorrow), describes the struggles of villagers, who are people affected by leprosy, who have big motivation and willingness to chase their hopes and dreams, despite of the sadness and sorrow caused by the discriminations they received. We wanted to tell the world about their strong motivation in this life, that would never be erased by the sorrow and painful moments they got from the society.

LCC Photo Exhibition 2017 showed some photos collection taken during the workcamp, and volunteers’ impression notes related with those photos. We wanted to show the real interaction between volunteers and the villagers to the visitor of our exhibition.

The things that we want to convey during the implementation of exhibition were 1. Leprosy as a health issue and 2. Leprosy as social issue.

For a point “leprosy as a health issue”, we give information below;

- Leprosy is a chronic infectious disease caused by *Mycobacterium leprae*. The disease in Indonesia is known as “kusta”. It is a mildly infectious disease, since more than 95% of the population has natural immunity or resistance against the disease. Leprosy mainly affects peripheral nerves & skin. Early symptom is pale or reddish skin patches with definite loss of sensations over the patches. In olden days, people affected by leprosy were isolated due to misconception about spread of infection and stigma and fear.
- The effective treatment is Multi Drug Therapy (MDT). The period of treatment is from 6-12 months depending on the type of the disease. If leprosy is detected and treated in early stage prior to developing nerve damage, patients can be cured without any disabilities. Deformities or ulcers are merely residual disability, and do not signify a sign of leprosy infection. Since the introduction of MDT in 1982, more than 17,000,000 patients have been cured in the world.

- Leprosy is a curable disease and after the treatment is working then people affected by it will not transmit the disease. When people know the information about leprosy, they will realize that leprosy is not dangerous. Within campers note, we share our experience with people affected by leprosy, within that we hope the visitor can open their mind about this issue.

Leprosy as a social issue, the thing that we want to say to visitors are

- Persons affected by leprosy and their family members must not be discriminated for whatever reason.
- Prohibition to mention lepers to people affected by leprosy. The use of proper term is the person affected by leprosy or when it is healed. the correct term is 'orang yang pernah mengalami kusta' in Indonesian and people affected by leprosy in English. Do not use OYPMK (abbreviation for orang yang pernah mengalami kusta)
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Before explaining information about leprosy and workcamp, we gave visitors a pretest to measure their knowledge about leprosy and their opinions about leprosy and leprosy discrimination especially that occurred in Indonesia.

After filling out the pre-test, volunteer will explain info related to the question, which is basic knowledge info about leprosy that is important to know to reduce discrimination against people affected by leprosy. Then, volunteers will again provide post-test to find out the change of knowledge and understanding of visitors after getting explanation about leprosy. The questions given in the post-test are as follows:

In the post-test, we asked the question "do you think, what can you do to reduce these social issues?" Because it's a way to encourage visitors to participate to reduce discrimination to people affected by leprosy, by doing simple things that they can do.



Exhibition about leprosy



Give explanation about villagers in Nganget

a. Visitors Description

During the 3 days of LCC Photo Exhibition, more than 150 people visited our booth. Visitors can read volunteer notes and photos displayed in the exhibition. There are several volunteers who stay in the booth to explain info about leprosy and workcamp to visitors who have an interest in the issue. During the 3 days of the exhibition, the most common question is how to discriminate against people affected by leprosy, whether leprosy can be cured, and what little things can be done to participate in reducing discrimination against people who have had leprosy.

The response from the visitors is quite good, some of them say that info about this condition (red: leprosy discrimination) is very rarely given in school, so people need such non-formal education to be more aware that there are health and social issues regarding leprosy that still occurs in the community.

b. Result

- In question number 1 on the post-test there are 109 respondents who answered correctly, and only 4 people who answered wrong. Almost all respondents have known that leprosy is a disease that attacks the peripheral nerves and skin. Typical symptoms that arise from leprosy is the presence of white and red spots and numbness in the skin area. After getting an explanation from the volunteer, in the post-test, there were 112 (99.12%) people who answered correctly, and only 1 respondent still did not understand the target organ of leprosy disease well.
- Question 2 on the cause of leprosy, only 48 respondents correctly answered in the pre-test and 65 other respondents did not know that leprosy is caused by bacteria, called *Mycobacterium leprae*. After the explanation by the volunteer, that leprosy is not a disease due to curses, witches, or descendants, but the disease caused by bacteria called *Mycobacterium leprae*, in the post-test, 110 (97.34%) respondents successfully answered the question, while 3 other respondents still do not understand about the causes of leprosy.
- The next question, about leprosy treatment, in pre-test, there were only 35 respondents who answered correctly, that leprosy can be cured by treatment called Multi-Drug Therapy (MDT), while 78 others still do not know about leprosy treatment using MDT. After conducting the pre-test, volunteers explained about leprosy treatment to visitors, that leprosy can be cured, using MDT, which is now easily accessible and free at every puskesmas in Indonesia. After the explanation, as many as 107 (94.69%) respondents correctly answered the question of leprosy treatment in post-test.

In the last question, only 58 out of 113 respondents have understood that leprosy is transmitted through interactions with untreated people for long periods of time and high frequency. Leprosy can only be transmitted by people who have not been treated medically, through long-term, high frequency interaction. When explaining the spread of leprosy, we emphasize that lepers who have received medical treatment, can no longer transmit leprosy, even though there is a disability in their body. If people understand that people who have been treated cannot transmit leprosy, then they will not stay away from people affected by leprosy and can interact normally with them without having to be afraid. After getting an explanation on the way of transmission of leprosy, 97 (85.84%) respondents become aware, and can answer correctly.

Accounting Report

Work Project

Income	Amount (IDR)	Expense	Amount (IDR)
Support from Sasakawa Memorial Health Foundation	9,136,000	1. Making Road	5,644,000
		2. Making Changing Room	3,499,000
Total	9,136,000	Total	91,43,000

Detail Expense for Work Project

1. Making Road

No.	Item	Volume	Expense
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1	Cement	33 bags	1,237,000
2	Wire size 6	7.5 rods	127,500
3	Wire size 8	12 rods	360,000
4	Small stones	4.5 trucks	349,000
5	Stones	0.75 trucks	300,000
6	Block	525 pcs	375,500
7	Sand (black)	1 dump truck	1,300,000
8	Sand	1 truck	370,000
9	Wire	1 kg	15,000
10	Rope 1	1 roll	5,000
11	Bamboo 1	13 rods	100,000
12	Bamboo 2	10 rods	200,000
13	Rope 2	2 rolls	40,000
14	Stain for painting	1 kg	70,000
15	Transportation for material	2 times	20,000
16	Hiring professional	5 days	425,000
17	Hiring assistant	5 days	350,000
Total			5,644,000

2. Making Changing Room

No.	Item	Volume	Expense
1	Cement	11 bags	429,000
2	Wire size 6	2.5 rods	42,500

3	Wire sizr 8	4 rods	120,000
4	Small stones	1.5 trucks	116,000
5	Stone	0.25 trucks	100,000
6	Block	175 pcs	124,500
7	Sand (black)	1 trucks	400,000
8	Roof tile	300 pcs	315,000
9	Galvalume ring	6 rings	210,000
10	Flame for roof	5 pcs	350,000
11	Nail 18cm	4 pcs	13,000
12	Pipe size ½	5 pcs	5,000
13	Pipe size ½ AW	1 pc	15,000
14	Pipe size 3 inch	1 rod	50,000
15	Connection pipe L ½	5 pcs	7,500
16	Drainage pipe	1 pc	10,000
17	Faucet	1 pc	8,000
18	Connector for faucet	1 pc	1,500
19	Glue	1 pc	7,000
20	Aluminum door	1 pc	135,000
21	Paint 1 (white)	1 kg	30,000
22	Paint 2 (waterproof)	5 kg	95,000
23	Paint 3	2 pcs	13,000
24	Paint 4	1 pc	20,000
25	Paint brush size 2	2 pcs	5,000
26	Paint brush size 4	2 pcs	6,000

27	Insulation tape	1 pc	1,000
28	Transportation for material	1 time	10,000
29	Hiring professional	5.5 days	475,000
30	Hiring assistant	5.5 days	385,000
Total			3,499,000