

Supporting Communities of Persons Affected by Leprosy

During the Coronavirus Pandemic through the “Sasakawa Model”

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1. Introduction

People throughout the world have felt the economic, social and health consequences of the novel coronavirus pandemic and persons affected by leprosy, many of whom were already in a vulnerable situation, are no exception.¹

Between April and May 2020, the Global Partnership for Zero Leprosy conducted interviews with more than 100 persons affected by leprosy from 25 organizations in 22 countries. It found that many had been seriously impacted by COVID-19 and measures against it.² In light of this, Sasakawa Health Foundation (SHF) conducted pilot projects in Indonesia, Bangladesh and Nepal between May and September 2020 to support communities of persons affected by leprosy amid the pandemic.

This commentary analyzes the achievements of these three pilot projects and the problems that were encountered, and examines what is necessary to properly support communities of persons affected by leprosy during the pandemic.

2. Outline of the pilot projects

In the pilot projects, persons affected by leprosy were positioned not as mere beneficiaries of support but as actors fully involved in carrying out the projects based on a three-pillar approach: 1) responding to the direct needs of the community (providing food, medication and other relief

¹ Leprosy is an infectious disease caused by the bacillus *Mycobacterium leprae*. Once incurable, it is treated today with multidrug therapy (MDT). Early detection and prompt treatment result in a complete cure. However, if treatment is delayed, the disease affects the peripheral nerves, leading to loss of sensation, impairments to the face, hands and feet, and can result in lifelong disability that contributes to the discrimination that patients, those who have recovered, and even their families face.

² The GPZL study found there were problems with 1) access to health services (treatment for leprosy and its aftereffects), 2) securing food and living supplies, 3) access to government safety nets, 4) ensuring stable livelihoods, and 5) access to information on preventing coronavirus infection.

supplies, and information on preventing the coronavirus; 2) advocacy (requesting local governments to guarantee access to existing support schemes and consider introducing new schemes); and 3) disseminating information (disseminating information via social media and other channels for the purpose of raising the profile of their organizations and gaining new supporters).

Given the organizational vulnerability of many such people's organizations, in selecting those to implement the projects, we made it a condition that they must have a track record of activities going back three years, and further, that they be assisted by a partner organization in order to carry out the projects more effectively. As a result, from among countries where leprosy is prevalent, we selected organizations that met these conditions in Indonesia, Bangladesh and Nepal. The pilot projects in the three countries are outlined below.³

	Indonesia	Bangladesh	Nepal
Implementation period	May to August, 2020	June to July, 2020	June to September, 2020
Target location	South Sulawesi Province 4 districts and 1 municipality (North Toraja, Jenepono, Bulukumba, and Gowa districts; Makassar city)	Rajshahi Division 4 districts (Bogura, Sirajganj, Natore and Pabna)	Terai region Province No.2 and 3, 4 districts (Dhanusha, Mahottari, Sarlahi, Sindhuli)
Outlay	20,300 USD	18,300 USD	15,300 USD
Organization of persons affected by leprosy	PerMaTa South Sulawesi (Founded in 2007, PerMaTa operates in 3 provinces including South Sulawesi which has 12 branches.)	Self-help organizations in 4 districts (Approx., 1,000 persons affected by leprosy participate as members, carrying out self-help activities, awareness-raising and advocacy)	Self-help groups in 4 districts (Each group is registered as an NGO in its region and conducts activities such as self-care training, awareness-raising and early detection.)
Partner organization	YDTI Acquired legal status as an Indonesian NGO in 2020; successor to DARE, a Dutch NGO conducting educational support projects for persons affected by leprosy in the province.	Lepra Bangladesh A branch of Lepra, an international NGO headquartered in the UK	Nepal Leprosy Trust Established in 1972, operates the Lalgadh Leprosy Hospital and Services Centre in the Terai region, providing treatment, care, support for economic self-sufficiency .

³ In Bangladesh and Nepal, beneficiaries of the projects included persons with lymphatic filariasis and persons with disabilities in addition to persons affected by leprosy.

3. Achievement and Challenges

3-1. Addressing the direct needs of the community

The outline of emergency assistance activities carried out in each country through the pilot project is as follows:

	Indonesia	Bangladesh	Nepal
Beneficiaries	511	1130	664
Details of support	1,345 food kits distributed multiple times(North Toraja: 300, Jeneponto: 300, Bukulumba: 145, Makassar: 300, Gowa: 300). Relief supplies varied from district to district, but included rice (5-10kg), cooking oil (1-2 liters), instant noodles (10-30 packets), eggs (10-30), dried fish (0.5-2kg), salt (2kg), spices (1-2kg), sugar (2kg) and vegetables.	Food and other supplies including rice (10 kg,) potatoes (2kg), beans (1 kg), onions (2kg), cooking oil (1 liter), masks (5), soap (2), detergent (500g) were provided to 730 people in Bogura and Sirajganj districts (631 persons affected by leprosy, 10 with lymphatic filariasis and 59 with disabilities) and relief money (1,000 taka per person) was given to 400 people in Natore and Pabna districts (311 persons affected by leprosy, 39 lymphatic filariasis and 50 with disabilities).	Food assistance consisting of rice (25 kg), beans (2 kg), cooking oil (1 liter), salt (1 kg), soap (2), masks (5) was given to 664 people (374 persons affected by leprosy, 131 persons with disabilities, 12 with lymphatic filariasis and 147 other socially vulnerable people).
Other	Ahead of the project, PerMaTa members took online training to learn basic information about COVID-19 and how to prevent it. In addition, they made advance visits to select those eligible for support, and distributed information on how to prevent COVID-19 as well as handing out soap and masks.	In addition to preparatory training for members of self-help groups (including the distribution of masks and disinfectant), 5,000 leaflets on COVID-19 and on nutrition were distributed and about 15,000 people received information.	Awareness-raising activities on preventing COVID-19 and on self-care for persons affected by leprosy that can be done at home were also implemented.

In Indonesia, 1,500 people in four districts and one municipality were initially scheduled to receive assistance, but the actual number was lower. It wasn't possible to obtain patient lists from every health center, and the lists that were obtained had issues (entries were incorrect, some patients had moved and others had died).

In Bangladesh, there were many cases of leprosy patients and persons affected by leprosy suffering from mental stress because of the struggle to survive and fear of the coronavirus. Lepira Bangladesh, which cooperated with the pilot project, provided mental health training for nine persons affected by leprosy who are expected to serve as counselors in the future.

In Nepal, a hotline was established for persons affected by leprosy and telephone consultations and counseling were provided. During the project period there were 234 consultations and 57 follow-ups.

3-2. Advocacy activities

In Indonesia, more than 30 meetings were held between the project team and the COVID-19 headquarters and related departments (such as the Infectious Diseases Division of the Health Bureau) in the four districts and one municipality that were the target areas of the project. Each local government provided emergency assistance (provision of food or financial support), but it was found that many persons affected by leprosy living in the target areas were not receiving it because 1) they did not have formal government identification, 2) they were not included in the list of support due to some circumstances, and 3) they did not know that support schemes existed or that they were eligible.

PerMaTa therefore approached the authorities to ensure that the persons concerned would be able to receive support. For example, in Bulukumba district, two people did not have ID cards and could not receive government support. In Jeneponto district, 21 people were not receiving government support and many of them were not aware they were entitled to it. In Makassar city, some people who had come from other districts to work were unable to receive support from the local authorities where they were currently living because their identity cards were from their hometowns.

Meanwhile, through door-to-door visits, it was found that many persons affected by leprosy and their families are still discriminated against, and the PerMaTa team set about addressing this issue too. For example, a 10-year-old girl in Makassar city was denied access to school despite being completely cured of leprosy; but after PerMaTa approached the school and requested that she be allowed to return, she was able to return to school safely. They also came across a woman being treated for leprosy in Gowa district whose husband had isolated her from the main house and who had to eat her meals and do her laundry by herself. When PerMaTa explained that she was no longer infectious now that she had started treatment, the husband promised that from now on he would support his wife during her treatment.

In Bangladesh, discussions were held with the social welfare and health and family planning departments in the four target districts on such issues as access to the existing old-age pension by persons affected by leprosy, and acquisition of legal status for the federation of self-help groups in each district. In passing, even though many persons affected by leprosy in Bangladesh are eligible for the old-age pension, they are not actually paid it. As a result of these meetings, the authorities said they would work with the federations to review the records and take steps to ensure that the pensions were paid. Further, because the federations did not have legal status as NGOs, they were

not officially recognized as the implementer of the projects, so the authorities have promised to cooperate in helping them to obtain the necessary legal personality.

In Nepal, meetings took place with 25 administrative authorities in the four target districts to obtain permission to carry out the project. In addition, members of self-help groups of persons affected by leprosy participating in the project cooperated with the administrative authorities to hold 10 "silent rallies" with a total of 282 participants, including persons affected, NGO staff, community leaders and government officials.

At that time, self-help group members submitted a number of requests in which they asked the authorities to: 1) maintain treatment for complications associated with leprosy at each health center; 2) treat persons affected by leprosy humanely during quarantine for the coronavirus; 3) implement campaigns to control leprosy and prevent the spread of the coronavirus in cooperation with self-help group members; 4) eliminate discrimination associated with the coronavirus; 5) analyze the impact of lockdowns and implement appropriate emergency assistance; and 6) provide assistance to register for free health insurance. As a result of these advocacy efforts, in Sindhuli district, the authorities proposed the implementation of a vocational training program for persons affected by leprosy.

3-3. Information dissemination

During the project implementation period, information about relief activities and stories about selected individuals were actively disseminated in the three countries through social media and other channels managed by each organization. A total of 81 posts was confirmed, some of which were reported on internet news sites.⁴

In Indonesia, a crowdfunding campaign raised around IDR 16,000,000 (US\$11,000) in just about a week to repair the home of a person affected by leprosy with disabilities. In Bangladesh, "Corona Fighters" were appointed from among persons affected by leprosy in each district, and were a symbol of support for their communities amid the coronavirus pandemic. In Nepal, a total of 3,008 public service messages were broadcast on four FM radio stations, heard by around 150,000 listeners.

⁴ If posts from the personal social media accounts of individuals belonging to each organization are included, the number is at least 10 times higher.

4. Conclusions

Based on the pilot projects, the following points were found to be key to effective implementation.

- **Ascertain whereabouts of beneficiaries:** Not all the persons affected by leprosy in the areas covered were known to the people's and partner organizations that carried out the project, so they needed to obtain accurate lists from their local governments and health centers. For example, in Indonesia, most of PerMaTa's members were from communities of persons affected by leprosy and so did not fully understand the actual situation of those living elsewhere, since the latter did not participate in self-help groups of the kind found in Bangladesh and Nepal. As a first step, therefore, it was necessary to ascertain the whereabouts of beneficiaries; how successful this effort was depended on whether each local government or health center cooperated in sharing lists, and whether the lists were accurate and this in turn had a bearing on the outcome of the project.
- **Involvement of people's organizations in process of selecting beneficiaries:** In order to distribute limited resources equitably, it is necessary to have an accurate grasp of the living conditions and needs of beneficiaries, and to be fair in selecting the destination of emergency relief supplies. The active involvement of the people's organizations in this process leads to ensuring fairness.
- **Providing relevant information through people's organizations:** Many persons affected by leprosy do not have sufficient access to the information they need to stay safe and well amid the coronavirus pandemic, including information on how to avoid infection, government support measures, and treatment of leprosy and its aftereffects. It was found that the people's organizations could serve as a communication channel between local governments and communities of persons affected, bridging the information gap and improving access to existing support schemes.
- **Exploring a new role for donors:** Since there are limits on our foundation's financial resources, as a donor we can contribute in other ways beyond granting funds by considering new roles such as providing advice and support for fundraising activities, for example, crowdfunding in Indonesia.
- **The importance of partner organizations:** The presence and role of partner organizations in supporting organizations of persons affected by leprosy is very important. In particular, partner organizations can make a significant contribution to achieving project objectives by compensating for those areas where people's organizations relatively lack proficiency, such as strategic planning, reporting in English and information dissemination. However, this assumes

that the partner organizations are familiar with the current situation and needs of the people's organizations and have built up a sufficient relationship of trust with them.

- **The ripple effect from people's organizations shouldering responsibility for projects:** By respecting people's organizations as central players in carrying out the projects rather than positioning them as mere beneficiaries of support, this makes possible activities that take into account their needs while also raising their own awareness of responsibility and capability.
- **Contribution of people's organizations to reducing stigma and discrimination:** In areas covered by the activities of people's organizations (e.g. where there are communities of persons affected by leprosy, or where self-help groups exist), their awareness-raising activities have produced results and there is relatively little stigma and discrimination toward persons affected by leprosy among the general population. Therefore, expanding the scope of activities of people's organizations can be a way to reduce stigma and discrimination.

5. Final thoughts

In November 2020, Sasakawa Health Foundation launched a new grant program for people's organizations based on the experience of the pilot projects described above, and has provided approximately 37 million yen (US\$340,000) in assistance to 22 organizations in 14 countries. In addition to supporting the three activity pillars that were the focus of the pilot projects—1) responding to the direct needs of the community, 2) advocacy, and 3) disseminating information—the new grant program has added a fourth pillar: implementation of capacity-building training for organizations to improve their ability to raise funds and continue their activities even after the project ends.

Given that persons affected by leprosy around the world are currently severely affected by the coronavirus pandemic, it is impossible for all their needs to be met through this support alone. And given that there is only so much that grant-making organizations are able to allocate for such projects, it is important to consider how to utilize existing resources effectively while at the same time cultivating sources of funding.

The "Sasakawa Model" described in this commentary is only one example of support being provided during the coronavirus pandemic, but by analyzing in detail the project outcomes and problems encountered faced, we hope this will help to improve the support measures for persons affected by leprosy to address the challenges they face.

【Reference】

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