



Good Practices

in Strengthening Participation of Persons Affected
by Leprosy in Leprosy Services



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The following organizations contributed to collecting good practices in strengthening participation of persons affected by leprosy in leprosy services:

ENAPAL (Ethiopia National Association of Persons Affected by Leprosy), DAHW (German Leprosy & Tuberculosis Relief Association) Colombia, HANDA (HANDA Rehabilitation & Welfare Association), Lepra Bangladesh, and LLHSC (Lalgadh Leprosy Hospital & Services Center).

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Sasakawa Memorial Health Foundation (SMHF)

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Foreword

Strengthening participation of persons affected by leprosy in leprosy services (SPP)*, utilizing their valued experiences of the disease, is one of WHO's global strategies to ensure and sustain quality leprosy services. Guidelines for strengthening participation were published by WHO in 2012.

SPP's contribution to leprosy control has recently been given more attention and importance than in the past. This is partly because leprosy has a low profile within health agendas due to the sharp decline in the number of patients over the past three decades and, as a result, the expertise of health care personnel in leprosy services is rapidly weakening. In addition, however, multifaceted leprosy issues require many other kinds of skills and expertise in addition to health and medical, including peer support and counseling, socioeconomic empowerment, and development.

SPP is taking place in many parts of the world, although the scale and scope differ given the diverse range of situations with regard to leprosy epidemiology, including the maturity of each group of persons affected by leprosy and the level of understanding and support of the national government and NGOs' programs. In this booklet, we introduce eight SPP cases in seven countries, which we believe cover these different situations, with the hope that they will provide concerned national health care personnel and NGOs with practical information to take concrete actions to start SPP. We also hope that these cases can help persons affected by leprosy recognize their experience with the disease as a valuable asset, and their potential to create a better society free from leprosy-related problems.

Finally, we would like to express our sincere appreciation for the significant cooperation and contributions to the compilation of this booklet by Ms. Kerstin Beise, Dr. Michael Chen, Ms. Hiroe Soyagimi, and other members of ILEP's Temporary Expert Group on SPP; also ENAPAL, DAHW Colombia, HANDA, Lepra Bangladesh, and LLHSC.

Sasakawa Memorial Health Foundation
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* Strengthening participation of persons affected by leprosy is in many cases now done by the Leprosy Control Programs or NGOs. However, there are cases where participation was first started at the initiative of the persons themselves and strengthened by their efforts. Therefore, in this booklet, strengthening participation of persons affected by leprosy (SPP) stands for both the active participation of persons affected by leprosy and the support given by the Leprosy Control Programs or NGOs to enable the persons to participate.

Bangladesh

Bogra Federation for Leprosy and Disability Development

A self-help group (SHG) federation of over 100 SHGs that successfully collaborate with the district leprosy control program on a number of leprosy services.

1. Bangladesh - Country background

Bangladesh is one of the world's most densely populated countries, with almost 160 million people and widespread poverty.

Although the elimination of leprosy as a public health problem was achieved in 1998, Bangladesh is one of the countries that still has a high incidence of leprosy, with well over 3,000 new cases detected yearly. The Ministry of Health and NGOs are doing a good job of providing MDT and support during the time of treatment. There is, however, a considerable shortage of attention before diagnosis and after the completion of treatment, as evidenced by a high Grade 2 disabilities rate and limited care after treatment is complete.

To improve the situation, the national leprosy control program cooperates closely with national and international NGOs. Stigma reduction, promotion of inclusion, and empowerment of persons affected by leprosy through, for example, the development of self-help groups (SHGs) is part of the leprosy program. Participation of persons affected by leprosy in leprosy services is actively supported by strengthening their capabilities, for instance identifying possible signs of leprosy in community members.

Situation in the area covered by the Federation

Bangladesh is administratively divided into eight divisions with 64 districts and 485 *upazilas* (sub-districts). Bogra district is part of the northern Rajshahi Division. It has 34 million inhabitants in 12 mostly rural upazilas. Around 27% of the population lives below the extreme poverty line, and literacy is low. Resources and access to rehabilitation services are limited. On average, about 80 new leprosy patients are detected annually in Bogra district.

2. Organizational background of the Federation

The Federation unites over 100 SHGs of persons affected by leprosy and other disadvantaged persons in the district. It represents the over 1,000 men and women who are members of these groups. Almost half of them are persons affected by leprosy; the other members have general disabilities or are otherwise marginalized.

The initiative to establish the Federation originated in the cooperation between an INGO and the district's health department. Experienced leaders of the upazila's SHGs were invited to form the Federation's executive committee of 25 persons, and were trained in various management and leadership

skills. The Federation began its work in 2014 and was **formally recognized as a community-based organization (CBO) by the government** in the same year. After initial INGO assistance, the alliance is now running independently.

The Federation seeks to act as a forum where SHGs can discuss their members' rights and needs for support, and to assist and strengthen the affiliated groups in their work. As an association of both people with different disabilities and those who are marginalized and vulnerable, **the Federation has a strong, united voice in advocacy.** Leprosy work and participation in leprosy activities undertaken by the local health department is an important element in the Federation's agenda. Members not affected by leprosy participate in these activities as well.



A quarterly federation meeting at Shajahanpur sub-district of Bogra district participated in by three leaders (Chairman, Secretary and Cashier) from each SHG

3. Participation in leprosy services

The Federation and its associations are active in seven main leprosy services:

- Finding people with possible signs of leprosy
- Supporting defaulters during their treatment
- Preventing disabilities
- Counselling for persons affected by leprosy and their families
- Socioeconomic development
- Awareness-raising
- Advocacy

Additionally, they have also started to participate in general community health work.

4. The Federation at work

4.1 Finding people with possible signs of leprosy

Members of the Federation have contributed considerably to finding new cases of leprosy.

How we work

Around 70 of our 1,000 members participate in finding people with signs of leprosy in their communities through different approaches: One way is to conduct, for example, **group meetings to inform people about suspicious signs** that should be checked at the health center. Another way is to **visit people door-to-door**, especially when we are involved as volunteers in contact surveys by the leprosy control program, carried out in the neighborhoods of newly diagnosed patients. Third, we **participate in school surveys** where we present basic information about leprosy to children, followed by a skin check by leprosy workers. Whenever we encounter people who might have leprosy, we encourage them to go to the health center for examination, and accompany them if needed. Visiting people with possible signs of leprosy in their homes of course bears the risk of being unwelcome due to people's ignorance and fear of leprosy; nonetheless, we have referred altogether over 100 "suspects." **We closely work together with the leprosy control program**, which welcomes and supports our involvement in finding new cases of leprosy.



A leprosy case detection campaign organized during World Leprosy Day 2018 in a remote area of Dhunot sub-district of Bogra district. Local community people are interested to know leprosy facts and happy with the opportunity to be screened for skin conditions in their own house/village/community. They also receive advice and care on other health problems.

4.2 Defaulter tracing and follow-up

Since 2015, the Federation has been supporting their fellow persons affected by leprosy during treatment, thereby contributing to achieving good completion rates. This is an important indicator of leprosy control.

How we work

We are in **regular communication with leprosy health workers** at the district and upazila levels. **Via mobile phone they keep us informed about patients** who have stopped picking up their MDT at the health center. We then go and **visit these people at home**, which is easier for us as we are living in the communities, closer to them – although transportation and communication problems are still common when we are out for activities in the field. We talk to them, explain the importance of regular medication and, because we have been cured from leprosy ourselves, **we present ourselves as positive examples**. We have already successfully supported around 50 defaulters this way.

We also support other people during their treatment, whenever they are facing problems. For example, we provide information about the prevention of disabilities and what to do when there are signs of a reaction. When necessary, we accompany people to get their MDT at the health center or for referral to other health services. **Via mobile phone we keep in contact with our peers**, and we always report back and consult with the local health workers.

4.3 Prevention of disabilities

Prevention of disabilities through self-care is at the heart of every SHG.

How we work

Despite our efforts to raise awareness about leprosy in the general community, negative feelings toward people with disfigurements and wounds seem inherent to human nature. We therefore assist our peers who have disabilities, and who often are neglected and isolated because of their disabilities. **We visit them at home to explain and practice self-care together**, and to help obtain assistive or protective devices they might need. If special footwear is necessary, we send information to partners who assist us with, for example, MCR sandals. For medical aid, we inform the leprosy control assistant who is ready to help.

As one important part of our regular agenda, **the SHGs of our Federation also practice self-care at their biweekly meetings**. If a member has an ulcer, he or she will be given special attention and the progress of the wound's healing is checked regularly. Our INGO partners support our self-care activities; they have provided training and support us with assistive and protective devices. The leprosy control program is ready to help when it comes to complications of wounds and other impairments, or if referral to the health center or hospital is needed.

4.4 Counseling

Peer counseling is done by members of the Federation individually and in groups.

How we work

We know that many persons affected by leprosy have low opinions of themselves; they feel less worthy than others and isolate themselves from society because of shame. Rather often they are not accepted by their families, and women affected by leprosy may be abandoned by their husbands. **We provide counseling to both our peers and to their relatives.** The family needs to understand what it means to have leprosy, so that they can unreservedly accept an affected member among them. For these one-to-one talks, we visit the people in their homes.

Counseling is also a part of our SHG meetings. **Together we discuss problems we are facing, and help people in distress by encouraging them to share their feelings.** We make sure that all members are aware of their rights and the availability and accessibility of services that might help them. With this knowledge, they can often find solutions for problems themselves.

4.5 Socioeconomic development

Hundreds of people affected by leprosy and their families in Bogra district have been able to improve their livelihood.

How we work

If we are poor, it is even more difficult to overcome stigma and social exclusion. Therefore, we pay a lot of attention to the socioeconomic empowerment of our members. **A vital activity in every group is a savings and loan scheme: To start such a scheme,** a new group first has to establish a basic fund from the contributions of its members. Every member pays 10 Taka per week, which is collected once or twice a month by the treasurer, who keeps the money in a bank account. At the end of the year, if there is a surplus, this money is divided back to the members.

To complement the basic fund, we received seed money from our INGO partner. Usually after six months, members can commence asking for a loan from the group, and, depending on the size of the proposal and the money available in the bank account, the group decides which requests are to be approved. The loans are paid back in monthly installments with an **interest rate of 10% a year**, divided into monthly installments. To protect our basic funds, the whole group guarantees the loan and ensures that it is paid back on time.

Apart from the savings and loan scheme, **we are also assisting our members in getting support from the government.** Financial aid is available from the Social Welfare Department, and other sectors provide, for example, goats or sewing machines to start small enterprises. The Federation acts as facilitator between members and the government. Since 2014, our SHGs have supported 800 people in starting income-generating activities. This assistance is also extended to the families of our members, for example for the education of their children.

With the support of the Federation, persons affected by leprosy received a disability ID card from the Social Welfare Department. They are now entitled to Safety Net Support from the Bangladesh Government, which includes a lifelong subsidy of 500 Taka a month.



4.6 Awareness-raising and advocacy

Limited awareness and understanding about leprosy and its consequences for people affected by it call for joining forces. People affected by leprosy play an important part in awareness-raising.

How we work

*On the one hand, **we aim to increase awareness about leprosy within our groups**, because we people affected by leprosy need to be knowledgeable about the facts of the disease and how to prevent consequences like wounds. We also need to be aware of our rights and how to increase our independence. On the other hand, **we want to create awareness in the community**. We conduct, for example, group information meetings and special activities on World Leprosy Day, and are involved in loudspeaker announcements. Almost 200 SHG members have voluntarily participated in these awareness-raising activities in their locality.*

*To raise attention on specific issues, **we advocate the matter at the respective government agency or, for example, in meetings with community leaders**. It is not always easy and straightforward for us to get access to people in the government. Our INGO partner provided us with training in advocacy and awareness-raising, and supports us with coordination and technical assistance.*



A local federation member holds a leprosy awareness session for villagers during an annual extended contact survey in Sherpur sub-district of Bogra in October 2017.



An advocacy meeting on leprosy organized by a sub-district federation with local government health staff and officials at Dhupchachia sub-district, supported by Lepra Bangladesh staff. In the meeting Md. Ali Ashraf, Chairman of the sub-district federation, is sharing their situation, challenges and expectations.

5. Impact

- **Positive development in leprosy control:** In 2015, 150 new leprosy patients were detected, twice the usual number of yearly cases.
- **Empowerment:** One of the key outcomes of SHGs has been the remarkable transformation of their members that further strengthens their participation in leprosy services. Having gained a better socioeconomic outlook and being aware of their rights in society, they are now contributing to the transformation of other people.

Mr. A.B.M. Shahid Sharif, Chairman of the Federation says:

“I am a transformed man. Now I can talk with logic, can demand my rights, and can plan what should be changed. Though often I feel desperate when I’m faced with uninterest from a stakeholder, the

group helps me to overcome these frustrations. After the official registration of our Federation as a CBO (community-based organization) I am now even more confident about the future.”

- **Unity:** Each SHG is a platform to assemble, discuss problems and hopes, and make plans to realize these hopes. The Federation plays an important role in coordinating all these aspirations and creates a **united strong voice** of people affected by leprosy and other vulnerable people through participation in leprosy services.

6. What motivates the Federation

The initial motivation and encouragement to form the Federation came from an INGO. The members of the upazila SHGs then realized the benefits of coordination, sharing and supporting on a broader district basis, and the power to speak with a united voice.

The Federation’s members derive **motivation from their ability to assist their peers** and other disadvantaged people in their communities.

7. Collaboration with the leprosy program and other stakeholders

- **Leprosy Control Program:** The Federation has established a relationship of mutual respect and close collaboration with the district and upazila leprosy control programs.
- **Other governmental sectors:** The Federation is increasingly able to approach and advocate their needs at other government sectors, such as the Youth Development Department and the Department for Social Welfare, and their responses are often, but not yet always, positive.
- **Local organizations:** Networking with various NGOs has resulted in regular communication, exchange meetings, and support for training.
- **INGOs:** The Federation is closely collaborating with an INGO, which is enthusiastic about its successful performance and contributions to the leprosy services in which they participate.

8. Promoting factors

What factors and support made it possible for the Federation to participate successfully in leprosy services?

- **Legal registration:** Registered as a community-based organization (CBO), the Federation now is able to organize formal programs and conduct its activities on a legitimate basis. This helps build commitment among its members and increases the Federation’s influence.
- **External guidance:** Third-party moderation by an INGO has been essential to keeping motivation high and activities running.

- **Experienced leadership:** A qualified management team is vital when setting up a federation. *The leaders of the Federation have gained experience through their previous involvement in upazila SHGs.* From this engagement they learned about the power of peer-support and group activities.

9. Challenges

What are the difficulties of participating in leprosy services, and how can they be overcome?

- **Limited capacities:** The majority of members of a newly formed SHG are poor, have little or no education, a low social status in their communities, and limited self-confidence. It is a great challenge to help these people in achieving empowerment. The group dynamics and peer support in regular meetings encourage members to share their feelings and to realize their rights and abilities.
- **Limited multi-sector support:** Despite good collaboration with local government agencies, their support is still relatively limited. Pro-active and practical assistance is further needed, for example, for appropriate care after cure.
- **Limited funds:** The Federation faces major challenges in running day-to-day activities.

10. Support

- **Support provided:** The Federation is primarily supported by an INGO that has provided, among other things, **facilitation, technical support, capacity building**, and other necessary materials. The Department for Social Welfare assisted them with **financial support** for people with disabilities, youth development training, and other areas. The leprosy control program supplies medical aid and footwear, and has been crucial in its **readiness to support the participation** of the Federation in leprosy control activities. Local NGOs have provided training and invited members of the Federation to attend their meetings and events, which helped to **develop skills in program planning and implementation**.
- **Support still needed:** The Federation still needs the **facilitation** of NGO partners to approach the government and access their support programs, mainly in the fields of funding, income generation, and legal proceedings. **Training opportunities** are much desired, for example in organizational strengthening, leadership, and livelihood development. The Federation hopes that **capacity building in specific leprosy control activities** like identifying early signs of leprosy and participating in contact surveys will be increasingly provided by the leprosy program.

11. Future plans

The Federation is committed to carrying on their participation in **community-based leprosy services**. The associations hope that local health departments engage people affected by leprosy in many more of the ongoing activities, particularly in community-based initiatives.

In addition to leprosy-related activities, the Federation seeks to become more engaged in non-leprosy community initiatives in the field, for example in areas like nutrition, deworming, disability prevention, and in attitude changes – for instance in the issue of child marriages.

Based on interviews with Mr. A.B.M. Shahid Sharif, Chairman of the Federation, six members, the local program manager of Lepra Bangladesh in Bogra, and the program organizer of the Bogra district leprosy program. Interviews conducted by Md. Mominur Rahman, Health and Community Development Officer, and Dr. Shahed Hossain, a scientist.

China

HANDA Rehabilitation & Welfare Association

A large and professionally working organization of people affected by leprosy who have been assisting their peers in leprosy villages of South China for 20 years.

1. China - Country background

In the 1980s, with the implementation of MDT, China's leprosy control moved from segregation to community treatment and rehabilitation. At the end of the 20th century, China reached the goal of eliminating leprosy as a public health problem with a prevalence rate of less than 1 case in 100,000. By 2013, the number of new cases detected had been reduced to below 1,000 each year. There are, however, about 200,000 people affected by leprosy who are still facing great challenges due to social stigma, more than 100,000 with serious disabilities, and about 20,000 elderly affected people who are living in 600 remote leprosy villages. Most of them have no families as the former quarantine policy had deprived them of their right to have family and children. Poverty, eldercare, psychological, medical, and rehabilitative support are the most urgent needs.

Situation in the area covered by HANDA

The southern provinces of China, where HANDA works, have always been among those with the highest numbers of leprosy cases. HANDA works mainly in the provinces of Guangdong, Yunnan, and Guangxi, and also with some mobile services in 11 other provinces. In Guangdong, Yunnan, and Guangxi, about 20,000 people are living in 203 isolated and remote leprosy villages; HANDA is working in 110 of these. Most of the people face extreme hardships due to disabilities, aging, stigma, and poverty. Transportation and communication in the remote areas are the other main challenges. As the people in the leprosy villages are getting older, eldercare and medical care have become their most pressing issues.

2. Organizational background of HANDA

Inspired by the founding of IDEA (International Association for Integration, Dignity and Economic Advancement), Dr. Yang Lihe, the founder of HANDA, started to organize people affected by leprosy in Guangdong in 1994. With the effort of Dr. Yang and a few people affected by leprosy, HANDA, standing for HANsen and DAmien, was officially founded in 1996 as a branch of IDEA in China. Today, HANDA has become a highly accountable NGO in China with over 5,000 members, 22 full-time staff - including three persons affected by leprosy - and thousands of volunteers.

The board of directors is the organization's highest decision-making body, and these directors are

elected by the members for a five-year term. In the early stages, members of the board had to be persons affected by leprosy. However, after some years of development, the board realized that people from other fields with other talents and thoughts should be included. From 2008, it was decided that **the board's membership could be up to one third non-affected members**, keeping a majority of at least two-thirds of leprosy-affected members. The board meets four times a year, and appoints a secretary general who is in charge of the organization's daily operations.



HANDA celebrated its 20th anniversary in 2016 at Wakintown Hotel in Guangzhou. Photo taken by Lin Chunsheng.

3. HANDA's participation in leprosy services

HANDA's activities are based on actual and urgent needs of people affected by leprosy, including physical, economic, social, and psychological rehabilitation.

HANDA's key activities today are:

- Prevention of disabilities and physical rehabilitation
- Socioeconomic development
- Empowerment and psychological peer support
- Networking and awareness-raising

HANDA's values are **equality, participation, empowerment, and dedication**, with the working principle: "Help people help themselves".

4. HANDA at work

4.1. Prevention of disabilities and physical rehabilitation

Self-care and provision of physical rehabilitation and assistive devices are at the core of HANDA's activities.

How we work

*In the beginning, with the help of volunteers, we provided wound care services to those in need. But gradually we changed our working methodology and started to teach people to help themselves instead of waiting for help. By appointing the **villagers to supervise self-care** in the villages and providing intensive peer support, and presenting successful model examples, we were able to promote the self-care among the people and have gradually expanded our coverage to more and more villages in all three provinces.*

*Apart from self-care, we provide protective shoes and tailor-made prostheses. As most of the people were living in remote and isolated villages, we developed a **mobile prosthetic workshop** that makes it possible for us to provide good quality prostheses and other devices in many provinces, rather than only in our main area of operations. We also help people to receive further medical treatment at local hospitals, when needed.*



Mr. Yuan Yuhua, a leprosy-affected prosthetic technician, is standing at far right together with the residents of Tingliang village in Guangxi. HANDA's prosthetic technicians visit this village three times a year on average. However, if anyone needs urgent help, more visits will be made. Out of 110 residents, 25 have received prostheses. Photo taken by Li Xuyang

4.2. Socioeconomic development

To enable sustainable economic development in leprosy villages, HANDA supports communities' efforts to build up their own community enterprises.

How we work

*We started our first trial in 1995, introducing in three villages, respectively, chicken breeding, fish farming, and cultivation of Chinese herbal medicine. For these enterprises to be successful, we had to go through a long process together with the villagers. Initially, we conducted field surveys and met with local governments to get their approval for using their land. We had to **ensure the active participation of the villagers and enable them to take part in the decision-making process and elect their own leaders for the enterprises**. We conducted skill training and study tours, and provided people with knowledge and skills in product packaging, marketing, and sales. Every week we travelled to the villages to monitor and support their economic activities. When people dropped out in the middle of the process, we tried to spend more time with them and build up their confidence. Today, 80 people affected by leprosy and 150 family members are still participating in these socioeconomic activities. Some of the early projects have meanwhile grown into comprehensive community development projects.*

Next to livelihood, we organized support for education and scholarships for children, and for the improvement of basic infrastructure and living facilities.

4.3. Empowerment and psychological peer support

HANDA is working hard to empower the leadership groups in its provincial branches as well as the residents of the leprosy villages.

How we work

*Initially, **empowerment workshops** were the main approach to connecting people and building up the leadership of the members. Then **leadership training and opportunities to attend meetings and events at different levels** provided great support to build up our self-confidence and the capacity of the leaders. At the village level, **networks among members** and between branches are important for providing psychological support and empowerment. The HANDA newsletter, published four times a year featuring contributions from members, is one of the main networking forums. Other activities, including a Chinese Chess Contest, Mutual Visits, and Photograph Groups /Painting Groups to exchange skills, are important approaches to networking and member empowerment. We, the members, are responsible for organizing the activities with the help of the staff and volunteers.*

*The board members and leadership group members regularly visit leprosy villages to provide peer support, help to build up the villagers' self-confidence, and promote mutual support among the villagers. **Member exchange visits** between villages provide opportunities to share experiences and skills among the members.*



At a Women's Empowerment Workshop in Longdongwan village, Lijiang, Yunnan Province, a HANDA team is giving a lecture on gender equality and the important roles that women play at home, in the village and in society. Photo taken by HANDA volunteer

4.4. Networking and awareness-raising

Developing and connecting with volunteers not only greatly promotes awareness-raising among the public, it also provides support to the people affected by leprosy in the villages.

How we work

We **work closely together with different volunteer groups** and organize exchange meetings and capacity building for the volunteers. In this way, we develop close connections with the volunteers and also enable them to use empowering approaches when helping the villagers, and become actively involved in awareness-raising activities. We have set up a database system for local supporters, which allows everyone to allocate resources effectively. We **use modern media tools**, including WeChat, a website, and charity platforms to promote our activities and raise awareness and funds. We also use, at every opportunity, conventional methods of promotion and advocacy, such as presentations at public events and interviews on TV, radio and in newspapers.

Ms. Zhao Fengying and HANDA volunteers in Yunnan Haigeng Park on the International Day for Dignity & Respect, 11 March. Photo taken by HANDA volunteer



5. Impact

- **Less impairment:** People have learned to help themselves and to carry out self-care. The physical condition of people affected by leprosy has greatly improved.
- **Enhanced economy:** More than 3,500 people affected by leprosy and their families have a better income, have access to education, and live in improved houses.
- **Social inclusion:** The self-confidence of people affected by leprosy has greatly improved. Neighboring communities accept and support them. People affected by leprosy now have **equal access to public and medical services, children are accepted in local schools**, and people can engage in fair trade.
- **Unity:** Connectedness among the villagers has improved. Through community enterprises and activities, people have realized the significance of unity.
- **Awareness in the government:** The government has become more aware of the needs of people affected by leprosy, and has, for instance, rebuilt houses, increased monthly subsidies, and provided medical insurance.
- **Personal change:** Being a member and working with HANDA was a pivot for change for many people.

Mr. Feng Keteng, President of HANDA, himself affected by leprosy, says:

*"Participating in HANDA opened my eyes to the wider world. My work is now respected by my peers; **my voice is heard and responded to carefully**. I realized that I have rights and I have the confidence to ask for them and to voice my needs."*

Mr Yuan Yahua, a leprosy-affected prosthetic technician, finds that:

"My participation in leprosy rehabilitation activities gives me positive energy. When seeing that people affected by leprosy are able to walk freely and comfortably with suitable prostheses, I consider my job a meaningful one. I feel surrounded by positive energy and even my family and friends feel this energy."

6. What motivates HANDA

People are motivated to participate in leprosy services with HANDA because they feel inspired by the commitment of, in the beginning, its founder Dr. Yang, and, nowadays, of its members. Members who are affected by leprosy are driven by the wish to do something for their peers, to help them to get up on their feet.

7. Collaboration with the leprosy program and other stakeholders

HANDA underlines the importance of working on good terms with the government. We have to cooperate with local governments in all the provinces where we are working. Furthermore, HANDA puts great effort into networking with other stakeholders like local NGOs, universities, and volunteer associations, and has successfully involved many people and institutions as active supporters.



Mr. Deng Wenxiang, Mr. Huang Liming and Mr. Liang Kangrun (from left to right) are discussing and reflecting on achievements made by HANDA in the last 20 years. Photo taken by Lin Chunsheng.

8. Promoting and supporting factors

What factors made it possible for HANDA to participate successfully in leprosy services?

- **Needs-based and result-based work:** HANDA identifies the actual and urgent needs of people affected by leprosy through **participatory processes**, and **regularly evaluates its work and progress**. It consistently adjusts its approaches based on evidence, therefore ensuring the effectiveness of work.
- **Integrating non-leprosy affected people into HANDA:** HANDA **invited people from a range of proficiencies to join the organization as board members** to ensure a broad perspective and long-term view on the development of the organization. The diversity of board members and their rich experience in organizational management has greatly helped HANDA in its strategic planning and future development.
- **Team work:** An organization is only as good as its members and how they work together as a unit to achieve high levels of results. The members and committees of HANDA have a strong feeling of **ownership and commitment to the organization**.
- **Continuous support from INGOs:** IDEA is an inspiring organization that has provided principles, guidance, and networking with other INGOs at an early stage. Later, a few INGOs provided not only funding support but also **technical support and capacity building**, which has helped HANDA develop into a professional and accountable NGO.
- **Cooperating with local organizations:** HANDA **cooperates and networks with local NGOs, universities, and other institutions**, and this has greatly expanded the organization's view to learning from others and building up a better governance and management system. It also helps HANDA connect with other local resources as well.

9. Challenges

What are the difficulties of participating in leprosy services, and how can they be overcome?

- **Stigma:** Despite all improvements, stigma and discrimination are still problems and pose obstacles to the implementation of HANDA's work. Awareness-raising is still one of HANDA's key priorities to address to this challenge.
- **Limited funds:** Funding by INGOs has been a main source of income for HANDA, but has decreased considerably in recent years. Local resource mobilization will become a priority for HANDA. Innovative approaches should be developed to ensure sustainable resources for the future.
- **Limited professionalism:** NGOs have a short history in China. It is always challenging to find professional staff with good NGO management skills and who are willing to engage in the field of leprosy. HANDA will on one hand provide capacity building to their own people, and on the other hand expand its services to cover a wider area and recruit professional staff and volunteers.

- **Limited participation:** Discrimination and self-stigma stop people affected by leprosy from participating in leprosy services. Aging is another issue preventing members from participating in HANDA's activities. HANDA will keep supporting people to help them regain self-value and try to reduce obstacles as much as possible, to ensure their participation.
- **Prevailing charity approach:** With the best of intentions, some organizations provide relief rather than encouraging development and empowerment, which stands in conflict with HANDA's principle of helping people to help themselves and increasing people's independence. HANDA will provide training and communication with different stakeholders to promote empowering approaches.

10. Future plans

HANDA will continue to respond to the actual needs of people affected by leprosy and focus on areas where there are huge needs, like Yunnan Province. While physical rehabilitation will always be an essential and ongoing program component, improving the lives of elderly people affected by leprosy will become a bigger focus. In line with actual financial challenges, HANDA will also put even more effort into the mobilization of local resources, in networking, and in collaboration with other foundations.

Last but not least, a statement by Mr. Feng Keteng, President of HANDA, could show the way to the longer-term future:

"I think, to solve the root of problems, it is not possible to rely on HANDA only, but it is a task of the government. HANDA should spend more time working with the government to make them realize their responsibility and how we can collaborate."

11. Lesson learned

- **Inclusive organizations:** HANDA profited from their decision to invite non-leprosy affected people with certain proficiencies to join the organization. These members eminently contribute to the capacities and expertise of the organization and its management.
- **Professional management:** A proficient operational and management system helps organizations obtain funding from donor organizations and governments.
- **Regular self-evaluation:** Needs change over the years. It is beneficial for the effectiveness of organizations that are participating in leprosy services to reevaluate their work regularly, so that they stay in touch with the real and actual needs of the people they serve.
- **Networking with local organizations:** To overcome their lack of manpower, HANDA has successfully tapped into the rich pool of volunteers not affected by leprosy, who are now supporting the goals of the organization.

Based on interviews with Mr. Feng Keteng, President of HANDA, and Mr. Yuan Yahua, member and P&O technician. Interviews conducted by Sally Qi, project supervisor, July 2017.

Colombia

Felehansen

A federation of regional organizations of people affected by leprosy that are committed to assuming responsibility in leprosy services and control programs.

1. Colombia - Country background

Colombia is a middle-income country in the northwest of South America, with a population of around 50 million. Despite a growing economy, the gap between rich and poor is large; 23 million Colombians are poor, with 6 million living below the extreme poverty line. In several regions, leprosy remains a major public health problem. The decrease in numbers of new cases is very slow, while late detection is common: 12% of new cases already have visible disabilities at diagnosis. The country's current prevalence is 0.27/10,000, but there are areas with higher rates. Annually between 400 and 500 new cases of leprosy are detected.

Main stakeholders providing leprosy services are the Ministry of Health and the Ministry of Social Protection, as well as a number of public and religious institutions and international NGOs. However, activities of the control program – including early case finding – have been reduced in recent years.

Situation in the area covered by Felehansen:

Felehansen represents 12 of the country's 32 departments, some of which still have comparatively high numbers of case detection – as, for example, Norte de Santander with 238 cases in the last five years. Stigma, discrimination, poverty, and ignorance of the disease, often reasoned by a strong religious component, are common issues.

2. Organizational background of Felehansen

Felehansen, the Colombian National Federation of People Affected by Leprosy, was established in 2014 with the aim of uniting the country's regional leprosy organizations. Currently it represents 700 people; 500 affected by leprosy and 200 not affected, through its nine affiliates and four associations not yet officially affiliated in the 12 departments of the country. The delegates meet at least once a year and have virtual meetings in between. The nine regional organizations conduct their own activities, while participating in the Federation's work plan as well. The leaders of the Federation assist the regional organizations with advice and guidance. All members work voluntarily. Those who benefit from governmental subsidies make small monthly contributions to the local organization they belong to, and to the Federation.

3. Participation in leprosy services

Felehansen strives to bring people affected by leprosy together and organize them, and to improve their lives through cultural, recreational, social, and community activities. To achieve this aim, they use community-based strategies. The Federation and its affiliated organizations are participating in the following leprosy services:

- Detection of suspected cases
- Home visits to help with treatment, POD and counselling
- Support for self-care groups
- Awareness-raising
- Advocacy for quality leprosy services
- Socioeconomic inclusion and development

4. Felehansen at work

4.1. Detection of suspected cases

Felehansen collaborates with regional leprosy programs to find and refer people with possible signs of leprosy.

How we work

*Our regional associations have already been looking for people with signs of leprosy for a long time; now, coordinated by the Federation, we have a work plan and can look for suspected cases more effectively. We have received training in how to understand the signs of leprosy and how to encourage people with the signs to seek examination. We **coordinate our activities with the respective regional leprosy program officials**, to inform them and get their support. Based on information and observations from the community, we list people who should be visited, and visit them. It is not an easy activity; people often refuse to accept the prospect of this diagnosis. Nevertheless, it has to be done; we cannot leave people undiagnosed as this would be a danger for the entire community. **We use our own personal experience when we talk with people.** We approach them with full respect for their privacy, their families and their social environment, and provide them with correct information, advice, and motivation. After diagnosis, we follow up with the people, and accompany them, when needed, during their treatment.*

On the occasion of World Leprosy Day in January, Dr. Cesar Robles, MD, of the Leprosy Program of the city of Santa Marta, Department of Magdalena, performs tests on a young child of a person affected by leprosy, who has been identified by Felehansen leader Enilda Fernandez as a suspected case of leprosy.



4.2. Home visits to help with treatment, prevention of disabilities, and counselling

Home visits to people undergoing treatment, to support and strengthen the patient and their family, are fundamental to the work of the Federation and its regional associations.

How we work

*We know that adherence to treatment is essential, so we contact people when they are starting MDT treatment, to reassure and inform them about the scope of the disease and encourage them to complete their scheme. **We talk with them, motivate and ensure them that we, who have gone through the same experience ourselves, are there to accompany them.** We inform them about the rehabilitative and economic support they can get from the government. We instruct them in how to prevent disabilities and guide them in doing self-care. We also tell them about the Federation and the benefits of being organized and united.*

Usually we receive information about people in treatment from the health services, while sometimes we also go from house to house. In some places we work together with religious communities, which have good networks and can help to approach people. The frequency of our visits depends on the person's needs: we are in regular contact with them and respond to their condition. When partners who support us in different aspects of our work join us on home visits, we adjust our work schedules to theirs.

*We have received challenging information about a young person in a rural area with difficult access who has been rejected by the family, specifically by the mother. **Our approach to such a case is to talk to the family first, to give them the opportunity to learn about the disease and the condition of the child, to be able to respond appropriately.** If we don't do this, it will be more difficult to intervene*

4.3. Supporting self-care

Self-care is at the beginning of every empowerment process.

How we work

*We put a special focus on self-care information and practice during home visits and also in self-care groups. People have to understand how the consequences of leprosy can lead to disability, and how important it is to be able to carry out safe self-care practices in all phases of the disease, including after treatment. **They need to realize that self-care and the prevention of disabilities is their own responsibility.** We explain and offer advice on how to use splints and other supportive devices, and when they should seek additional treatment. It is not easy to get people's full understanding, especially when they are elderly or have little education, and to get them to commit to purchase items they might need to protect their eyes, feet, and hands.*



A person affected by leprosy in a rural area of Norte de Santander

Leidy Jhoana Pineda, along with other members of Felehansen, makes visits to the municipality of Norte de Santander to teach persons affected by leprosy how to do self-care of eyes, hands, and feet.



4.4. Awareness-raising

Felehansen members argue that all human beings have compassion and don't need to be "sensitized," but **many people lack knowledge about the disease, are misinformed, and are therefore afraid.** This makes it necessary to educate people about leprosy.

How we work

We have identified different target groups that we want to reach with our message:

- *Of great importance in the Colombian context are **health professionals, who sometimes don't know enough about the consequences leprosy can have** for those affected by it.*
- *The same is true for the general public – people in villages and cities.*
- *In particular, we approach young people in schools and universities, who have open minds and hopefully may come to be a new, more tolerant generation.*
- *It is also vital to approach the church. Since leprosy is mentioned in the Bible, it is important to encourage religious authorities to convey a helpful and empowering message to their congregations.*
- *Organizations of other people with disabilities are another crucial target group: **All people with disabilities should work together with one voice.***
- ***Local governments need to be aware of leprosy and its consequences;** they will then be more likely to promote supportive programs for people affected by leprosy.*
- *Last but not least, **families and people affected by leprosy themselves need to be properly informed.***

*Our members receive training about the facts of leprosy and how to raise awareness. We use brochures and other IEC materials, and **we are eager to join any regional or national events and conduct media interviews to spread our message.** We give educational talks at care centers, and of course also use our home visits to spread correct information about leprosy.*

Maribel Pérez, a person affected by leprosy, teaches people in the community about leprosy with other members of Association of Bolívar, a member of Felehansen, on the occasion of the World Day of Disability in the city of Cartagena.



On the occasion of World Leprosy Day, leaders of Felehansen sensitize people in the community about leprosy in a vulnerable area of the city of Cartagena. Approximately 60 to 100 people participate in the event aiming at ending the stigma against the disease.



4.5. Advocacy and involvement in governance

Felehansen advocates for quality leprosy services and a more prominent role for people affected by leprosy in those services.

How we work

*When advocating for quality leprosy services, we used to act and intervene when a problem was already there. Now, we want to promote awareness and action before a problem is at hand. **We want to become real actors and take part in decision-making and the planning of programs and activities.** In collaboration with the local governments, we want to become involved in monitoring the leprosy control program, to further improve quality health care. **Health services suffer from a lack of adequate human resources. This is where we can contribute with our specific expertise.***

We have made contacts across a wide network, and spread information about our organization. We are still developing our proficiencies and we believe that, for now, our main achievement has been our recognition as an organized association that represents people affected by leprosy in Colombia.



Leaders representing Felehansen meet with Dr. Ernesto Moreno in charge of the leprosy program of the Ministry of Health and Social Protection (MSPS) of Colombia to promote the development of actions for the benefit of people affected by leprosy in Colombia and to end the stigma of the disease.

4.6. Socioeconomic inclusion and development

Many people affected by leprosy are still isolated and lack job opportunities in their society, because often they were unable to achieve advanced levels of education, and many of them are elderly and require specific attention for income generation.

How we work

*As most people affected by leprosy live in poverty, they need work, education, and housing. We as an organization have no resources to support them directly, but **we can serve as a bridge to find help.** So far, we can only support income-generating projects on a very small scale. **We mainly try to channel people's requests for support to our donor partners.** When a partner supports an income-generating project for a person affected by leprosy, we accompany this person and his or her family during the start-up of their enterprise.*

Sometimes we can also assist people in obtaining vocational training. Our aim is to create more income-generating opportunities and new jobs.

5. Impact

- **Unity:** Felehansen's main achievement has been its recognition as a federation that represents a large number of people affected by leprosy through its regional organizations. The significance and need for such an alliance is reflected in its growth and development. Despite all challenges, the members feel great satisfaction in being organized, in not being alone, and in **having a united voice in overcoming the consequences of leprosy.**
- **Knowledge:** They had to educate themselves, starting from scratch, to be able to participate in any activities. Today, they consider **their greatest strength to be the knowledge they have acquired about the disease and its consequences.** Now they understand that it is nothing they did wrong, but that they are facing external factors including the ignorance of other people.
- **Reduced stigma within families:** People affected by leprosy are rarely rejected, but supported by their families during treatment.
- **Personal change:** Participation in Felehansen's activities has changed the lives of its members:
"Since I am participating in Felehansen's activities I feel more vital, I leave my house several days a week, walk a lot, visit peers and try not to let my disability limit me."
"My daughter encourages me to continue working for Felehansen. The rest of my family is surprised that I'm following so many activities. I lost my fear and I feel calm, now that they know about the disease. I will continue working so that others feel better."

6. What motivates Felehansen

Members feel inspired by the prospect that their **own experiences with leprosy can now help other people** who are going through the same process:

"I like to give witness with my life to help my peers, answer their concerns, and encourage them to complete their treatment."

*"We believe that **with our experience we can support others affected** and be useful to prevent disabilities in them."*

Members know from their own experience that the diagnosis of leprosy can have a significant psychological impact on people, and that having company, especially in the first months, can be essential. They have a strong wish, therefore, **to complement the leprosy program, which cannot provide such intensive support.** Similarly, they believe that **early case detection can be done much more effectively with their participation.**

7. Collaboration with the government's leprosy program and other stakeholders

Felehansen collaborates with the Ministry of Health at the national level, while the regional associations work together with the Departmental Secretaries of Health. This led, in 2017, to the development of a project with the government that aims to encourage more people affected by leprosy to participate actively in leprosy control services. They also cooperate with hospitals, religious communities, and several national and international institutions of various backgrounds.

8. Promoting factors

What factors made it possible for Felehansen to participate successfully in leprosy services?

- **Working as a federation:** Access to a wide range of experiences and expertise was possible, and as a result they formed a strong united voice with which to advocate their cause.
- **Strong desire to help others:** Members of Felehansen have a strong commitment to helping their fellow persons.

9. Challenges

What are the difficulties of participating in leprosy services, and how can they be overcome?

- **Learning:** The biggest challenge for the members of Felehansen was learning, as they had not been participating in similar activities before; they had to start learning from zero, a challenge especially for those with little education.
- **Limited funds:** The Federation needs to communicate and collaborate with nine affiliates all over the country and wants to invite more organizations to join the Federation, but lacks the resources. Both the Federation and its affiliates face difficulties in funding their activities. While some of the affiliates have managed to conclude agreements with government institutions, others have not yet been able to obtain income to finance their activities, and obtaining the commitment of regional authorities is challenging.
"It can be tiring to see the urgent needs but not to have enough resources to help and to reach everybody."

The Federation hopes to grow and represent all people affected by leprosy in Colombia so that in dialogue with the government, their voice would have more weight.

- **Limited participation:** Taboos and myths around leprosy are still common. It is often difficult to encourage people who are scared and isolated, especially elderly people with little education who have lived their lives in poverty, to become involved.

10. Support

What support made participation in leprosy services possible? What support will be needed to continue the participation?

- **INGOs:** They have provided funds, motivation, guidance, and training on a wide range of issues from technical aspects to human rights and community-based rehabilitation.
- **Governments:** Some regional associations were able to secure funding from their local government. Regional health departments provided training and shared information on leprosy.

External support for funding, training, guidance, and moral support are still needed for organizational strengthening and subsequent better recognition, especially from the government.

11. Future plans

Felehansen and its affiliates will continue their activities and hope to reach the remote and rural parts of Colombia where needs are greatest. They plan to inspire more of the younger people affected by leprosy to become active, and will work to expand the number of affiliates and reach as many people affected by leprosy in the country as possible.

Felehansen will expand their network with other stakeholders, foremost with the government at the national and regional levels. They will approach more national and international support organizations and hope to learn from similar projects in other countries.

12. Lessons learned

- **The initial trigger:** People affected by leprosy who have lived in isolation and humiliation often have little confidence for starting an organization all by themselves. An external trigger is needed to get them organized and to start participating in leprosy services.
- **Long-term support:** Continuous motivation and support by a partner enables organizations of people affected by leprosy to go successfully through the process of empowerment, self-recognition, and organizational development.
- **The power of being organized:** Despite all challenges, people affected by leprosy who participate in leprosy services feel great satisfaction in being organized, in not being alone, and in having a united voice in overcoming the consequences of leprosy.
- **Importance of guidance:** Felehansen developed a proposal for a joint project with the government and won funding from an INGO for it. This shows that with guidance and support, even a young organization can do fundraising and support itself.

Ethiopia

Shashemene Leprosy Affected Persons Association

A branch of the national organization ENAPAL that has been providing peer support in a large leprosy settlement for 20 years

1. Ethiopia - Country background

Ethiopia is a landlocked country in Africa with over 102 million inhabitants. It has a fast-growing economy, yet still ranks as one of the poorest countries in the world. One of Ethiopia's central health problems is communicable diseases worsened by poor sanitation and malnutrition.

Ethiopia eliminated leprosy as a public health problem in 2000, but about 3,600 cases are still detected every year. The proportion of children as a proxy for ongoing transmission among these new cases is high. In many regions of the country stigma is a serious problem. People often seek nonconventional treatment to avoid recognition and social rejection at health centers. Default rates are high. Divorce, unemployment, and displacement with severe economic, social, and psychological consequences are common. Even today, new leprosy settlements are created on unauthorized land without basic amenities like drinking water, electricity, and roads.

ENAPAL, the Ethiopian National Association of Persons Affected by Leprosy, was founded in 1996 to re-integrate people affected by leprosy and their families into society.

Situation in the area covered by the Shashemene Association

Kuyera in the Shashemene region is one of the biggest leprosy settlements in Ethiopia. As a measure to rid the capital from the "shame" of leprosy, during the first half of the 20th century people affected by leprosy were forcibly moved to the settlement, 240 kilometers from Addis Ababa. In the 1960s and 70s, the total number of residents reached 5,000 people. Today, around 600 people affected by leprosy and their families live on the premises. Throughout the years, they have experienced recurrent eviction and violent conflicts with the original inhabitants of the area, but now enjoy more harmonious relationships with their neighbors.

2. Organizational background of the Shashemene Association

Shashemene Leprosy Affected Persons Association was established after people from the Kuyera settlement were sent to the ALERT leprosy center in Addis Ababa for treatment, where they were introduced to the rights movement by ENAPAL. Inspired by this example, they founded the Shashemene Association in 1997 as one of the 70 local branches of ENAPAL. The Association has been working since then in the Kuyera settlement.

The Association is legally registered at the local level as a nonprofit organization. Every four years, elections are held at all ENAPAL branches, including Shashemene. The leaders of the subdivisions follow the general statutes of ENAPAL and have responsibilities in management, implementation of activities, and networking. The Shashemene Association has 875 members, all leprosy-affected residents of Kuyera and surrounding regions. Except for severely disabled and aged persons affected by leprosy, all members pay a membership fee.

3. Participation in leprosy services

“People affected by leprosy who are healthy and economically well off will find it easier to overcome stigma and discrimination”.

Based on this maxim, the organization aims to address the social, economic, and medical problems of the large population in the Kuyera settlement. Through direct assistance and advocacy at local and regional levels, they participate in:

- Prevention of disabilities
- Socioeconomic development
- Awareness-raising and advocacy

4. The Shashemene Association at work



A couple affected by leprosy in front of their house



Association leaders visiting a leprosy patient in hospital



Association leaders visiting a family affected by leprosy for needs assessment

4.1 Prevention of disability

Disabilities are the cause of discrimination, dependency, and poverty for people affected by leprosy. By encouraging people to work proactively to prevent disabilities, the Association supports their social and economic empowerment.

How we work

*Initially, four competent and well-accepted members of our Association were selected and trained by leprosy experts at the national level to become trainers in self-care management. Returning to the settlement, they conducted local training sessions to share their knowledge and skills with the other members. We then **formed small self-care groups** with 10 members per group in our neighborhoods; 80 self-care groups are running in Kuyera today. The groups have developed their own schedules and routines for regular meetings. Once a month, we come together to practice self-care and discuss issues related to impairments, while enjoying each other's company over a cup of tea. A coordinator helps us organize referrals to local hospitals for further treatment when complications arise. Our groups also pay attention to other issues. We have, for example, just recently identified three people with relapse, who were then referred to the Shashemene referral hospital.*

4.2 Socioeconomic development

To improve the economic situation of people in the settlement, the Shashemene Association also facilitates a number of self-help groups.

How we work

Our income-generation groups have been set up with the support of our partners, both national and international NGOs. We members of the Shashemene Association are responsible for running the groups. We conduct a variety of income-generating activities including poultry production and fattening, and we organize and monitor savings and credit schemes. A total of 570 families have benefited from our income-generating activities, educational support, and housing assistance.

4.3 Awareness-raising and advocacy

Raising awareness of leprosy is a key priority of the Shashemene Association. Late diagnosis and social exclusion can be prevented once communities understand leprosy better.

How we work

*We want to reach different target groups with our awareness campaigns. First of all, the **general community** needs to understand leprosy so that they stop stigmatizing and excluding us. We also approach sectors of **the government** - the labor and social affairs departments - to ensure that they have a correct understanding of leprosy and accordingly increase their commitment for support. Last but not least, **our peers, people affected by leprosy and their families**, are in great need of knowledge and awareness about the disease, so that they can overcome self-stigma and be accepted by their families.*

We organize events to raise awareness; for example, community discussions where everybody can contribute their ideas about how to reduce stigma. We have celebrated World Leprosy Day every year since 2000. We involve religious leaders to help spread a correct message about leprosy and we directly advocate with the government for the rights of persons affected by leprosy and their families.



Monthly meeting of the Association's members

5. Impact

- **Social inclusion:** More than 200,000 people in the area surrounding the settlement have been reached by the Association's awareness campaigns; as a result, people affected by leprosy are now better included in community. They can participate in community activities more often, and marriages of persons affected by leprosy into the non-affected community have even become possible.
- **Regained lives:** Many people escaped a life of loneliness and self-stigma. Peer support in self-care groups helped them to build up **confidence to take control over their own health and disabilities**.
- **Enhanced economy:** Many people improved their livelihood through self-employment and income generation in the self-help groups. The housing situation is better and more people are able to send their children to school.
- **Rights enforcement:** Through the efforts of the Shashemene Association, 120 people evicted from their land regained their entitlements and property. People affected by leprosy are now participating in local government affairs.

6. What motivates the Shashemene Association

After their many hardships, the members of the Shashemene Association are **committed to help people affected by leprosy** in the settlement and beyond to lead a better life.

7. Collaboration with the government and other stakeholders

The Shashemene Association works with local and international NGOs and above all with ENAPAL. They collaborate with the government to carry out awareness-raising in the wider community.

8. Promoting factors

What factors have made it possible for the Association to participate successfully in leprosy services?

Organizational groundwork: Two significant aspects contributed to the successful organization of the people in the Kuyera settlement:

- Before the Association was established, ENAPAL created awareness in the settlement about the importance of **solidarity among people affected by leprosy**, and of being organized.
- The Association has been registered and obtained **an official license**. This allows the members to operate with full entitlements and gives them the confidence they need to speak out about their rights and needs.
- **Training of trainers:** The Shashemene Association profited from training-of-trainers (TOT) courses for their members. When these trainers returned to the settlement, they shared their knowledge with all the other members and could then establish a large number of self-care and self-help groups.

- **Independence:** Although the organization still benefits from financial and professional support, they have, **thanks to their membership fees**, achieved a level of sustainability that enables them to continue fighting for their rights without being overly dependent on external parties.

9. Challenges

What are the difficulties of participating in leprosy services, and how can they be overcome?

- **Stigma and discrimination:** In the wider community around the settlement, stigma and discrimination are still strong and people have deep-rooted misconceptions about leprosy. To overcome incorrect notions about leprosy, the Association involves religious leaders who have a strong influence in community.
- **Self-stigma:** People's low self-esteem is still a barrier in their fight for dignity. The Association continues to work on building up their members' confidence. Participating in their activities is an important step toward enhanced self-worth.
- **Limited recognition in the government:** The local government is not always fully aware about the contributions people affected by leprosy can make in leprosy services. The Shashemene Association focuses on partners who already acknowledge their contributions. They continue advocating with the local government to raise awareness.

10. Support

What support did the Shashemene Association receive to make their work possible, and what support will be needed to continue working?

ENAPAL has been the chief supporter of the Shashemene Association. Together with a number of national and international NGOs, resources that have been provided include:

- **Funding:** Financial support for income generation, housing, educational support for children, running costs for self-care groups, and many other activities;
- **Capacity building:** Members of the Association have participated in various training courses, of which the TOT courses for self-care groups have been particularly effective.
- **Technical support and guidance:** ENAPAL and other NGOs have supported the Shashemene Association with guidance and advice on how to build up their self-care and self-help groups, and on their path toward empowerment.

The government supports the Association by providing the land for their office, assistance with income-generating activities and legal support, and mobilizes the wider community in awareness programs.

Support still needed

The Association hopes for continuous funding for income generation and awareness campaigns to reach as many people as possible. They hope that stakeholders, including the local government, will further increase their commitment.

Despite being an independent organization, they hope that project- and program-based interventions by ENAPAL and international NGOs will be carried on.

They urge their members to show even more commitment, initiative, and energy to participate in the organization for the development of the Kuyera settlement and its surroundings.

11. Future plans

The Shashemene Association wants to broaden and strengthen its services in collaboration with the Ministry of Health and the Ministry of Social Affairs. They discuss plans to share and possibly duplicate the model as it has been implemented in the Kuyera settlement in remote ENAPAL branches.

12. Lessons learned

- **Training-of-trainers:** TOT courses for members of leprosy associations have been an effective approach to capacity building in Ethiopia, reaching a large number of people affected by leprosy.
- **Legal registration:** Legal registration of the organization helps its members feel recognized and gives them security when they advocate their causes.
- **Preparation before forming an organization:** ENAPAL helps to raise awareness among people affected by leprosy about the benefits of being organized, before inviting them to join such an organization.
- **Autonomy:** The Shashemene Association has been able to carry on its activities for 20 years because it is relatively independent through its monthly membership fees and income-generation projects.

Based on interviews with the vice-chairperson of the Association. Interviews conducted by Tesfaye Tadesse Haile, ENAPAL Managing Director, August 2017.

India

Sam Utthan

A small, energetic organization of people affected by leprosy in Bihar that supports peers with the legal issues they face

1. India - Country background

India, with its population of over 1.2 Billion, has the highest number of people affected by leprosy in the world. Despite achieving the elimination of leprosy as a public health problem at the national level in 2005, every year around 135,000 new cases are detected. Of these, 4,500 already have visible disabilities at the start of treatment. People affected by leprosy are still among the country's poorest citizens, often with no other option but to beg. India had around 800 leprosy colonies as of 2017, where people were once isolated and still live today.

Situation in the area covered by Sam Utthan

The state of Bihar has 38 districts, with a total population of 104.1 million. The prevalence rate for leprosy is 0.91 per 10,000 people; elimination (less than 1 case in 10,000 people) was achieved only recently. People affected by leprosy live either with their families or in one of the 63 colonies. Stigma and discrimination are still an issue, with many people being caught up in a vicious circle of poverty, humiliation, disability, and begging.

2. Organizational background of Sam Utthan

Sam Utthan means "Equal Development for All". It is a registered NGO of people affected by leprosy working in both leprosy colonies and general communities in Bihar. The establishment of the organization was preceded by an initiative of the National Forum of India, the precursor of the Association of Persons Affected by Leprosy (APAL), with support from an INGO in 2011, which conducted **a country-wide survey of leprosy colonies and identified leaders among persons affected by leprosy** to organize people in leprosy colonies. This resulted in the formation of Bihar Kusht Kalyan Mahasangh, which later became Sam Utthan. In addition to the survey, another important event that contributed to its firm establishment was the vicious attack on a leprosy colony aiming to evict poor people from their houses to take over their land. The new organization swung into action immediately. Inhabitants of colonies stood in unity with the organization. The government was forced to take action against the wrong-doers and reinstate the forcibly evicted people.

Today, Sam Utthan has 11 members, all of whom are affected by leprosy, including two women. The members live in different areas of Bihar, both in colonies and in general communities. They have equal

responsibility over all 38 districts and 63 leprosy colonies, but in practice where attention can be given depends on availability and distance. The members meet once every three months and communicate frequently by phone and, if internet is available, by email. Activities of Sam Utthan are mostly in response to issues raised by persons affected by leprosy or identified by them in their interactions with those people. Sam Utthan works in close collaboration with INGOs and APAL, which provides guidance and support for their activities.

3. Participation in leprosy services

“From the very beginning of our organization, we stood up for the rights of persons affected by leprosy. We work for the welfare and well-being of persons affected by leprosy. Reducing stigma and re-installing dignity are very important for us.”

Sam Utthan supports people affected by leprosy through the following activities:

- Assisting people in securing their entitlements to government support
- Prevention of disabilities
- Counselling
- Awareness-raising

4. Sam Utthan at work

4.1. Assisting people in securing their rights to government support

Sam Utthan takes up legal and rights issues of persons affected by leprosy and helps them obtain fair solutions.

How we work

We receive information about people in need from health centers or from people who previously benefitted from our assistance. We visit these people at their homes to see what the matter is. Often they need correct information and we help them to apply for governmental support. If they face any further difficulties, we go with them to the respective authorities.

*We also **provide information** to the communities in the colonies about services that are available to them, opportunities for education and training, support for livelihood and housing, and the provision of pensions, ration cards, and the Indian biometric identification card. We educate people about their rights and entitlements, and teach them how to apply and where to file reports.*

*In cases of rights abuse, we collect evidence and **conduct peaceful demonstrations and strikes** to get the attention of the authorities involved.*



Mrs. Rachna Khumari, a member affected by leprosy of Sam Utthan, is participating in a human rights training program in Bhubaneswar, Odisha State, in October 2014 organized by the Association of Persons Affected by Leprosy (APAL). Both affected and non-affected persons participated.



Mrs. Rachna Khumari joins the strike in 2014 to demand the start of the Bihar Welfare Scheme



Newspaper report showing Mrs. Rachana Khumar, a member affected by leprosy of Sam Utthan, is attending a press conference where Mr. Acharya Divyadarshi, Chairman of Bihar Satabdi Kusht Kalyan Yojna (Bihar Welfare Scheme), says that persons affected by leprosy in Munger are not getting the benefits of this welfare scheme.

4.2. Prevention of Disabilities

The members of Sam Utthan guide and encourage their peers to practice self-care and help them access rehabilitation services.

How we work

We always make the most of our **home visits to peers**. Depending on the individual needs, we explain how to do self-care and encourage people to do so regularly, or organize protective and supportive devices for them. We either visit people regularly to monitor and support them during their treatment, or we respond to calls for help when there are special incidents.

In some colonies we **organize weekly self-care groups**, which we attend to support the members. We help explain self-care techniques, take foot measurements for protective footwear, and mobilize people to practice self-care regularly. As part of an integrated POD project, we also look at people with lymphatic filariasis and support them. If there is need for additional treatment, we refer people to the responsible institutions.

4.3. Counselling

Sam Utthan provides counselling services on an individual basis and during self-care camps.

How we work

People in need of counselling may face discrimination within their families, be unsure about their leprosy treatment and its consequences, or face economic hardship due to disabilities or discrimination. We visit them at home to **give them correct information and counselling about leprosy**, the treatment, and economic support that may be available from the government or other service providers. We also talk to families and communities to raise awareness of leprosy. In cases of reactions or other complications, we advise the person to report to a referral center.

4.4. Awareness-raising

Sam Utthan shares facts about leprosy, both with general communities and with people affected by leprosy and their families.

How we work

To increase awareness and correct knowledge about leprosy in general communities, we **collaborate with other leprosy organizations** to carry out mass awareness programs, rallies, and anti-leprosy activities. We approach other local organizations to explain leprosy and the advantages of inclusion, with the aim that they may invite persons affected by leprosy to their activities or as members.

Leprosy awareness for us also means that we ourselves know our rights and have a correct understanding of leprosy. We therefore work with the residents of colonies and provide this kind of knowledge to them.

5. Impact

- **Reduced stigma:** The work of Sam Utthan has contributed to greater acceptance and respect within families and among friends. In general communities, a positive change in attitude toward leprosy is noticeable.
- **Participation in governance:** In the early days of Sam Utthan, members were timid and hesitant to go to a government office and meet with officers. Now, after many opportunities to practice and with heightened self-worth, members have become increasingly confident to discuss issues with government officers.
- **Unity:** Sam Utthan unites people in settlements across Bihar. Incidents of injustice toward persons affected by leprosy are reported to the organization and taken up by them. Persons affected by leprosy who live in general communities approach the organization as well, and ask for their support.
- **Enhanced economy:** As a result of a campaign by several leprosy organizations including Sam Utthan in 2013, a monthly pension scheme was created by the Bihar government. Many people who were still rejected for pension support received help from Sam Utthan and are now benefitting from the scheme.

6. What motivates Sam Utthan

Members feel inspired by the happiness they see in a person who finally receives support from the government's welfare scheme. They have learned how important it is to stand together, **to be organized and represented**, and to defend their rights. They want others to experience the same.

7. Collaboration with the leprosy program and other stakeholders

Sam Utthan's main partners are APAL and an INGO. The INGO created the **position of lokdoot (ambassador)** for members of Sam Utthan, and integrated this position into their own programs.

Sam Utthan collaborates with other local NGOs with the aim of increasing the number of available services, and is in dialogue with the government at the block and district levels to advocate for social entitlements for people affected by leprosy. As yet, however, there is no current collaboration with the leprosy control program in, for example, early case detection.

8. Promoting factors

What factors made it possible for Sam Utthan to participate successfully in leprosy services?

- **Community mobilizer:** Creating the position of **a community mobilizer – lokdoot (ambassador)** – has given Sam Utthan's members a clear role to identify with, and the opportunity to act as an interface between people affected by leprosy and leprosy /welfare programs.

- **Initial trigger:** Before the formation of Sam Utthan, people lived isolated lives. They needed an **external initiator** to start organizing them. APAL and an INGO were able to provide this initial encouragement and guidance.
- **Opportunity to build confidence:** Various **opportunities to participate in meetings and events**, from the local to international level, have contributed considerably to building Sam Utthan's members' confidence and enabling them to advocate successfully for the needs of their peers.

9. Challenges

What are the difficulties of participating in leprosy services, and how can they be overcome?

- **Limited awareness about the benefits of participating:** Sam Utthan is involved in leprosy services, but not in the activities of the leprosy control program. New initiatives and projects are needed to promote participation by persons affected by leprosy in leprosy control programs.
- **Limited number of partners:** Until now, only a limited number of organizations have been working with Sam Utthan on advocacy. Sam Utthan needs to increase its efforts to work with other rights-based organizations.
- **Limited participation:** People affected by leprosy in general communities do not like to associate their name with leprosy. They are reluctant to join the group. Sam Utthan hopes to offer more opportunities for these people to participate in social activities, which will encourage them to become more active.
- **Organizational weaknesses:** Sam Utthan is aware of a number of aspects of their organization that still need to be improved. Accepting women in management is one of them.
- **Limited funds:** Sam Utthan members are constrained in their work by financial difficulties and family responsibilities. Travelling long distances, conducting periodical meetings, and upscaling successful activities are difficult when funding is limited.

10. Support

- **Support provided:** Sam Utthan is primarily supported by an **INGO** and the **national DPO APAL**. The support includes **technical support and guidance** for legal registration and for establishing linkages with the government and other stakeholders, **providing opportunities** to attend a wide spectrum of training schemes and to participate in national and international platforms and events, and **financial support** for the implementation of projects and activities.
- **Support still needed:** Sam Utthan still requires more **capacity building** in managerial skills. They will need **financial support** to fund activities, as well as motivation and advice to carry on.

11. Future plans

Sam Utthan wants to further develop their organization into a leading institution addressing the needs of people affected by leprosy. They will try to increase their membership to successfully operate in all districts. The organization also hopes to improve their own competences to attract people affected by leprosy with leadership skills to join the organization so they can scale up their activities, support more people, and collaborate with the government to engage in leprosy services.

12. Lessons learned

- **Power of empowerment:** People affected by leprosy and their organizations, like the members of Sam Utthan, can effectively take up legal issues and help, very practically, defend the rights of their peers.
- **Distinct positions:** Creating distinctive positions for people affected by leprosy who want to participate in leprosy services can be beneficial. It generates confidence and security.
- **Importance of offering opportunities:** Offering people affected by leprosy opportunities to participate in meetings and events from the local to international level contributes considerably to building their confidence and enabling them to work for their peers.
- **DPO partner:** New organizations of people affected by leprosy benefit immensely when a more experienced DPO (of people living with disabilities including or not including those related to leprosy) contributes to guiding and advising them.

Based on interviews with Rachna Kumari, Kamlesh Divyadarshi and Ram Barahi (Board members of Sam Utthan). Interviews conducted by Vijayakrishnan, August 2017.

Indonesia

PerMaTa Gowa

A small district branch of the national disabled people's organization PerMaTa, whose young and energetic team supports peers in collaboration with the district leprosy program.

1. Indonesia - Country background

Indonesia has a population of over 260 million, spread over an archipelago of more than 17,000 islands. Worldwide, it has the third-highest number of new leprosy cases per year, after India and Brazil. Over a third of the 34 provinces still have a prevalence of more than 1 case per 10,000 population. Active transmission and late detection are serious issues. The number of people with visible disabilities at the time of detection is high.

People affected by leprosy used to be isolated in leprosy settlements. All of these villages have officially been closed for many years, but residents keep living there for lack of alternatives. Newly diagnosed people, however, now remain in their respective communities. As people of pre-MDT generations, who often had severe disabilities, become fewer, stigma is not that prominent anymore, but can be still high in certain areas. Stigma is a severe problem for many, and counselling for these people is only provided infrequently.

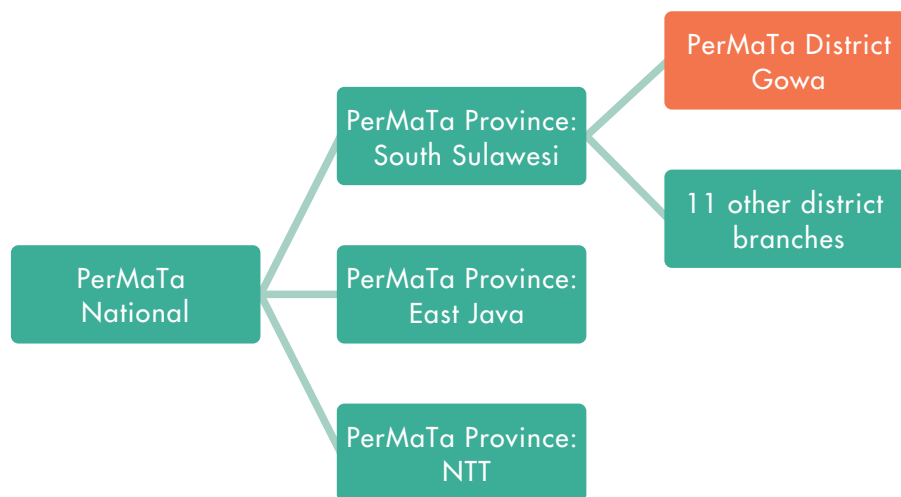
Situation in the area covered by PerMaTa Gowa

The district of Gowa in the province of South Sulawesi still has a high caseload of people affected by leprosy, which again differs within its sub-districts. As many as 9% of new cases have visible disabilities. Gowa has only one former leprosy settlement in a remote mountain area. All other people affected by leprosy live in general communities. Among the rural population, stigma can be severe. Gowa has active and often outstanding leprosy control program personnel.

2. Organizational background

PerMaTa stands for Association of Independent Persons Affected by Leprosy. The Gowa branch is a small but very energetic and predominantly female branch, established in 2012; the provincial PerMaTa branch asked a leprosy health worker in Gowa for a list of young people affected by leprosy, 11 of whom were invited to a meeting and encouraged to start the Gowa branch. They began from scratch, had no self-confidence and no idea of what to do. The provincial PerMaTa branch offered guidance, and INGOs supported training. **Leprosy health workers in Gowa provided moral support and shared their knowledge with the young people.** The organization developed quickly and is now, five years later, though still small, one of the most active PerMaTa branches in Indonesia.

Twenty members are registered, all of them affected by leprosy. Only five members, however, are active. Their area of operations covers three sub-districts. The members of PerMaTa Gowa are not employed, nor do they receive any fees for their work. If in the course of their work they happen to receive any financial support from partners or stakeholders (transport, lump sum), they contribute 5% to the PerMaTa Gowa cashbox. The group doesn't meet on a regular schedule, but only when they are planning an activity, which may happen daily or monthly. Since they don't have an office, they meet at a centrally located member's house.



3. Participation of PerMaTa Gowa in leprosy services

PerMaTa Gowa's vision is to stop stigma and discrimination and help eliminate leprosy. Their participation in leprosy services covers three fields:

- Supporting individual people before, during, and after their treatment
 - Encouraging suspected cases to seek examination
 - Home visits to help with treatment, POD, and counselling
 - Supporting existing self-care groups
- Awareness-raising
- Advocacy for quality leprosy services

4. PerMaTa Gowa at work

4.1 Supporting individual people before, during, and after their treatment

Home visits are the organization's key activity. From their own experience, the members know how important it can be to have a friend, motivational support, and to know that one is not alone.

How we work

We receive information about people with possible signs of leprosy from local organizations or community members. We look at their signs and encourage them to go for an examination at the health

center. **At this stage, we avoid the word leprosy** and don't tell suspects that we had leprosy ourselves, because some people and even more so their families can become very angry when they think they are suspected of leprosy. Later, usually, people are very grateful for the information and the encouragement we could give them.

Concerning people in treatment, leprosy health workers in Gowa provide us with names and addresses of new patients, or tell us about patients in need of extra support. As phones are not always available, we don't make appointments but just go and visit. We always go as a team because this makes the work more enjoyable, easier, and safer. The frequency of our visits depends on the needs; sometimes we come only two times during a year of treatment, sometimes weekly. After treatment we usually do check-ups, and stop visiting if we see that the person is well.

We tell people in treatment that we are affected by leprosy as well. We talk with them and their families about leprosy, the treatment, side effects, signs of reaction, and self-care. Almost half of the people we visit don't know much about leprosy, they isolate themselves and are frequently tempted to stop their treatment. **We can use ourselves as examples** to point out what can happen when medicine is not taken regularly, but that leprosy can also be cured without visible remains. We accompany people to the health center or the hospital if needed, and even pick up MDT for them when someone is not ready to go for themselves. "Counselling" is very important: We cannot counsel people like psychiatrists do, but we listen to them, help find solutions, provide correct information, and show them they are not alone.

In addition to home visits, we also assist self-care groups (SCG) that are run at some health centers. Initially, an INGO invited us to support the SCGs, although we didn't know much about self-care ourselves. Over the years, we became facilitators for these SCGs. The prevention of disabilities is extremely important to us, because this is what leprosy is all about – the fear of ending up as beggars at the side of the road, holding wounds and stumps out to the public.



A PerMaTa Gowa member measures the foot of a self-care group member for protective shoes at the health center in Gentungan, Gowa district, South Sulawesi.



A PerMaTa Gowa member helps a person affected by leprosy to go and collect MDT from the health center.

Three members of PerMaTa Gowa (seated at right) explain about leprosy during a home visit.



4.2 Awareness-raising

PerMaTa Gowa believes that correct information about leprosy is vital to ending stigma and by extension leprosy.

How we work

Every one of us frequently talks to other people about leprosy. We use every opportunity to make others aware of the facts about leprosy. We even wear leprosy t-shirts to trigger questions about leprosy. As an organization, we hold information events at middle and high schools. It is easiest at high schools where the students already understand and are ready to listen. These events are initiated and organized by us. Leprosy health workers attend the events, but they leave the stage to us.

*To stand in front of a class, **we must be ready to admit we had leprosy. It takes courage and involves a process to get to this point. Our members are all at different stages of this process.** Some of us still have not told our neighbors or wider family that we had leprosy, but are ready to talk to school children in a different part of the district. The children usually react only positively and are happily surprised because we don't look like beggars in the streets. We tell them that we had leprosy only at the end of the session, because at that point the students already know what leprosy really is.*



IEC activity by Yuli, the leader of PerMaTa Gowa, at a high school in Pallangga, Gowa district

4.3 Advocacy

This is a newer activity for PerMaTa Gowa, which started when they were invited by the local government to participate in the development of a district bylaw for quality services in leprosy, TB and HIV/Aids.

How we work

We organize workshops and visit relevant district departments in order to secure their commitment to the bylaw. Ideally, there should be a number of local organizations involved, but so far it is mostly we who are active. We fortunately have the assistance of a former INGO worker who has a legal background. He helps us on a volunteer basis.

5. Impact

- **Positive development in leprosy control:** In the three sub-districts where PerMaTa Gowa works, leprosy has recently become less of a problem. Very few new people are detected, and usually they are detected before they develop disabilities. There are only a few people with severe wounds. These improvements can be credited to the local leprosy control workers, with PerMaTa Gowa having a supporting role.
- **Reduced stigma:** Today, many more people know about leprosy. While two or three years ago, the parents of most members did not allow their children to join the organization, they now have realized that their children are invigorated by helping others.
- **Regained lives:** The most immediate impact of PerMaTa Gowa's work can be seen in the many individual persons they have helped during their treatment and afterward, people who successfully finished medication and regained self-worth. One young farmer said:
"Without the visits by PerMaTa Gowa, I might not be here today."

6. What motivates PerMaTa Gowa

A member of the organization explains:

"I was stressed, depressed, and alone. I never believed I was really cured from leprosy until the leprosy health worker finally sent PerMaTa Gowa to me. Only then did I realize that there is a life after leprosy. Now, I want to help others in the same way."

Another member shares:

"It is very satisfying to tell a person: I had leprosy too, don't stop your treatment! You will get better!"

7. Collaboration with the leprosy program and other stakeholders

PerMaTa Gowa closely collaborates with several health centers in the district. **The leprosy health workers of these centers realized that these young people can assist them in their work:** Patients are more likely to finish their treatment on time and without complications when they are helped by PerMaTa Gowa. Sometimes, even, patients don't want a government worker to come near their house, for fear of being discovered by their neighbors; at such times, the members of PerMaTa Gowa step in.

A leprosy health worker, who has worked for the district's leprosy and tuberculosis control program for many years, says:

"They assist me. I don't have the time to visit patients more frequently; my time is occupied with TB. Therefore, I ask them to give more intensive support to the people affected by leprosy."

To ensure smooth collaboration with the leprosy program during awareness campaigns, there is a **strict division between medical and non-medical information:** All medical questions are directly handed over to leprosy program officers.

8. Promoting and supporting factors

What factors made it possible for a small organization like PerMaTa Gowa to participate successfully in leprosy services?

- **Working as a team, not alone:** The members of PerMaTa Gowa form a strong team. They **carry out most activities, for example home visits, together as a team**, because:
"In this way work is more fun and we can keep our spirits high."
- **Flexible time management:** The members of PerMaTa Gowa work voluntarily and, accordingly, have limited time. They try to fit in leprosy work next to their other duties at home and work. Home visits became their key activity as they then can decide themselves when and whom to visit, making work much easier than, for example, following the fixed schedules of self-care groups.
- **Moral support:** Moral support and motivation are vital for going all the way from no self-worth to an efficient team of dedicated, self-confident, young people. PerMaTa Gowa received this backing from leprosy health workers and the provincial PerMaTa branch.

9. Challenges

What are the difficulties of participating in leprosy services, and how can they be overcome?

- **Limited funds:** A local leprosy NGO financially supported PerMaTa Gowa for a while, and an international leprosy NGO provided funds for certain projects and times. Lack of funding is a great challenge for PerMaTa Gowa. As the members work voluntarily and cover travel and other expenses themselves, the scope of their work is very limited. They wish to expand, but simply can't.

The organization wants to learn how to write proposals to engage in fundraising, and hopes that the leprosy control program will start supporting them.

- **Limited participation:** The limited number of people affected by leprosy who are willing to participate in leprosy services is another challenge. As most people have families or work that keeps them busy, they cannot afford to work voluntarily. Some still have self-stigma and are afraid that others might know about them. Others simply lack the motivation and don't care because they are already cured, or don't see the benefit since there is no money to be made. The active female members face the problem that once they get married, their husbands might not allow them to continue working.

PerMaTa Gowa always invites young people undergoing treatment to attend their meetings and activities.

- **Limited multi-sector support:** Arranging permits for awareness-raising campaigns or inviting stakeholders for a workshop can be difficult for a young and small organization.

PerMaTa Gowa underlines the importance of collaboration with the district health department and leprosy control program to help them to approach stakeholders.

10. Future plans

The dream of PerMaTa Gowa is to become a larger organization that will be able to work in the entire district of Gowa and beyond.

For this to happen, they will need to find funding to cover at least their members' expenses. They hope that the government will acknowledge their contribution and support their work.

11. Lessons learned

- **Advantage of a small organization:** The small team of PerMaTa Gowa profits from strong relations of friendship and a greater flexibility that allows its members to tackle challenges.
- **Teamwork:** To participate in the organization's work, not every member needs to be on the same level of empowerment and accomplishment: they can contribute according to their individual capacity, complemented by others.

An organization of people affected by leprosy can utilize the fact that its individual members have had different experiences with leprosy to motivate their peers, who also are facing different issues (e.g. reactions, disabilities, and stigma).

- **Clear task divisions:** The participation of people affected by leprosy is of great advantage for leprosy control programs. When collaborating, a clear description of the tasks people affected by leprosy are able to fulfil is helpful in preventing overlaps into purely medical spheres that are the responsibility of the medical leprosy program staff.

Based on interviews with members of PerMaTa Gowa. As an additional source for information, the leprosy worker Ms. Herawati was questioned. Interviews conducted by Kerstin Beise, August 2017.

Indonesia

Enterprise Self-Care Group (KUK)

A self-help group in a former leprosy settlement that has been providing self-care guidance and micro-finance services to its members for more than 10 years.

1. Indonesia - Country background

Refer to Country background for PerMaTa Gowa.

Situation in the area covered by KUK

KUK is located in a former leprosy settlement named Jongaya in Makassar, South Sulawesi, which was once one of the largest leprosy settlements in Indonesia. Today, mostly elderly people affected by leprosy and their children and grandchildren inhabit the densely built-up area, but there are also still people affected by leprosy who are only in their 30s or even 20s. The standard of living has improved significantly over the past few decades, but economic conditions are still a problem, especially for those who are elderly with disabilities and little education. Access to governmental services and programs like health insurance is limited, and there is a chronic lack of access to medical rehabilitation, despite a hospital just bordering the area.

2. Organizational background of KUK

KUK is the abbreviation for 'Enterprise and Self-Care Group'. **The informal group has no legal registration; nevertheless, they have set strict internal rules and regulations for themselves.** KUK started as a self-care group (SCG) in 2005, initiated by an INGO. In 2008, the members began savings and loan schemes.

The group started with 10 participants, and in its peak times has had 50 members. Currently, 32 members are active in KUK. Most of them are middle aged or elderly, and the majority are female.

KUK management consists of a chair, a vice chair, secretary, and treasurer, elected by the members. In the early years, the leaders were called "self-care assistants" and received a small fee from the leprosy control program. Later, when fees were discontinued, the group decided to grant the management team a reimbursement for their efforts in the form of a small percentage from the interest on loans.

3. KUK's participation in leprosy services

Members of KUK argue that because income generation is not a responsibility of the government's leprosy control program, people affected by leprosy need to support each other to become empowered both economically and socially. The main activities of KUK are therefore:

- Prevention of disabilities
- Socioeconomic empowerment
- Motivational peer support to enjoy life

Some members of KUK are also members of PerMaTa, a DPO of people affected by leprosy. They encourage other KUK members to join awareness campaigns and World Leprosy Day celebrations.

4. KUK at work

4.1 Prevention of disabilities

KUK members support each other in practicing self-care and together organize medical or rehabilitation support.



A weekly self-care meeting organized by KUK visited by Dr. R. Soldenhoff, a leprosy doctor, at the soaking place of Jongaya community, Makassar, South Sulawesi.

How we work

In the beginning, we met in an empty community room and brought our soaking basins with us from home every time. Later we decided that to attract more people, we should have our own permanent meeting place. The city health services allowed us to use the veranda of their unused health station, located centrally in the settlement. **The provincial leprosy control program built concrete soaking basins and later added a roof to shield against the sun and rain.** Today we have three permanent soaking places with roofs. We take the water to fill the basins from a neighboring house and all of us contribute some money to pay for the water.

When we started, **three of us volunteered as “self-care assistants”** to keep the meeting place in order, remind members of the meeting schedule, help them with self-care, footwear and other problems, and keep record books for all our members. As self-care assistants we had **special t-shirts and our position was acknowledged in the settlement.** The provincial leprosy control program paid us small fees in the early years. We also had external help from an INGO, which visited regularly to provide guidance.

For self-care we use materials that everybody can afford, like strips of cloth to cover wounds. If people need new special footwear or help with their prosthesis, we rent a car using our own group money and make an appointment with the local leprosy hospital. At times, the hospital team has even come to the settlement, and announced their visits through KUK.

Over the years we have received many visitors from all over Indonesia and even from abroad, who came to see and learn from our group. In 2015 we decided to stop self-care activities at the soaking place, because after 10 years we are all very experienced and can do this at home. We continue our regular meetings for the savings and loan system and we still know exactly who has a wound or not; we keep supporting each other in doing self-care.

4.2 Socioeconomic development

KUK is well-known for its successful savings and loan system.

How we work

We began with running an “*arisan*,” a traditional savings cycle, where each member puts in a fixed small amount of money every week, and one member is drawn to get the entire weekly savings. We did this very successfully, and then started a real savings and loan scheme. Later we added more sub-groups, for example to produce handicrafts together.

We developed the savings and loan scheme together with an external facilitator from an INGO. We discussed and **decided on clear rules**, functions of group members and ethical codes, and put this all in writing. These rules and regulations are very important, and as a result, we have very good repayment rates and are able to continuously provide new loans to our members. From the 1% interest on loans we also organize social activities. Once, for example, we went together to a local beach; for many of us it was the first time in our lives. We also run a sub-group that conducts religious gatherings and teachings to build people’s character. And at the end of each year, we distribute part of our profit back to the members and some is set aside to help people in great need in the settlement, like elderly people.



Pak Mursalim, a person affected by leprosy and a member of PerMaTa, trains KUK members in household economy, Makassar, South Sulawesi.

5. Impact

- **Less impairment:** Many residents of the settlement have deformed feet and hands, meaning they have frequent wounds that are difficult to cure and that often recur. While these people previously ignored their wounds, they now manage to keep them under control, by doing self-care, resting, or seeing a doctor when needed.

"We became aware and more confident that we can deal with our wounds. We would not hide our feet and hands anymore but accept them as they are and care for them as much as possible."

- **Enhanced economy:** Many members took one or several loans and started successful enterprises. Repayment rates are good because of group pressure and strict rules.

"KUK is our support line. If we wish and need, we can borrow money with very little interest. We are friends and we help each other."

6. What motivates KUK

- **Being a member:** Before KUK, people had many wounds and nobody did self-care. They learned how to clean wounds from the nurses at the leprosy hospital, but had no motivation to take care of them themselves. With KUK, self-care became popular. More and more people joined the group, and they were able to get advice and help from KUK members for their ulcers that were difficult to heal. **The meetings were also a village event**, so people came because they felt entertained and found an opportunity to meet others.
- **Being a leader:** The KUK leaders are motivated by the **acknowledgement of their unique position**, both by INGOs and the government, as well as by other KUK members and peers in the settlement. Additionally, they feel responsible for and committed to keeping the group and its successful activities running, and are therefore willing to spend time and energy on them.

7. Collaboration with the leprosy program and other stakeholders

At first, the city and provincial leprosy control program supported KUK. Its members were asked to attend meetings and workshops to **help the health trainees** with first-hand accounts of the needs of persons affected by leprosy. They were also invited by the medical faculty of a local university and by the leprosy training center to act as examples for students' examinations. Participants recalled:

"The teachers used to joke that the KUK members are more knowledgeable about leprosy than the doctors."

The group also works together with several DPOs to, for example, share skills in producing handcrafts. PerMaTa (Association of Independent Persons Affected by Leprosy) helps to gain access to rehabilitation and social programs.

8. Promoting and supporting factors

What factors made it possible for KUK to participate successfully in leprosy services, by supporting self-care practices and offering microfinance services for people affected by leprosy?

- **Peer support:** KUK members live together in one settlement and know each other well, which gives them the advantage of having strong group coherence as well as group pressure. KUK members say:
"Most important is to support each other. Those who successfully heal their wounds become role models for others. Those who repay their loans and start a small enterprise show others how to do it."
- **Independence:** KUK members were encouraged from the start to decide for themselves what their group should look like and how it should function. The KUK management team was **given and assumed full responsibility** and performed its tasks with diligence and discipline.
"We want this group to run, so we make it run. It is for our own benefit."
- **External guidance:** External facilitation by an INGO, using an empowerment approach, was essential in the beginning.

- **Rules and regulations:** The **strict set of rules** and disciplined management team are key factors that support the success of the SHG.

“We handle things like a big family. But with rules.”

One regulation, for example, says that people have to do self-care and start saving before they can get a loan. Another regulation obliges members to form small circles of three persons who have to guarantee for each other's repayment of loans. If one cannot repay, the others have to do it for him or her. Strong peer pressure and close monitoring is the result of this system.

The set of KUK rules and regulations can be found as Annex.

- **A good and visible place to meet:** The permanent soaking place has always been a major motivating factor for people in the settlement to attend meetings. It is a visible **reminder to come together, like a clubhouse**. People have planted flowers and vegetables and put pictures on the walls. Its central location makes it easy to reach.
- **Financial acknowledgement:** In the early days, the self-care assistants received a small fee for their service from the leprosy control program. This showed the group that the leprosy program really cared and **regarded their activities as important**. Seed money was provided by an INGO.

Training was given by different I/ NGOs and DPOs.

9. Challenges

What are the difficulties of participating in leprosy services, and how can they be overcome?

- **Keeping motivation high:** For KUK, despite its good group dynamics, it is a challenge to keep people motivated, active, and willing to spend time for the group, next to their obligations to family and work.
KUK set up a rule that people have to attend meetings in order to get a loan.
- **Limited support for rehabilitation:** Support from the health services for special footwear, prostheses and other assistive devices and services is limited, which prolongs the feeling of being inferior and unworthy.
KUK works closely with PerMaTa, which helps them approach institutions and access services.
- **Internal conflicts:** The group has gone through different internal conflicts and problems, but was able to solve all problems in one way or the other.
Strong leadership and peer pressure are essential to getting “troublemakers” “back in line.” External mediation has been necessary in a number of instances.

10. Future plans

KUK is now independent and doesn't necessarily require financial support to carry on their activities. They hope to become a legally registered organization, which would allow access to funding programs from the government to develop their savings and loan scheme.

As KUK's members get older, regeneration is needed. Most young people in the settlement are not affected by leprosy; their families, however, are generally poor. These young people would profit from joining the enterprise group, but need guidance to understand and accept the rules and to build up successful enterprises. To initiate and facilitate this, KUK members feel that they need external support.

11. Lessons learned

- **Sovereignty:** An independent self-care/help group can run sustainably, without continuous external support. Their savings and loan scheme can be so successful that they are able to use the income even from low interest to help others in need.
- **Good management:** Clear regulations, goals, and work plans have enabled the KUK SHG to run their activities successfully and sustainably.
- **Recognition:** Acknowledgment is essential to the strengthening of an organization of people affected by leprosy. This may include the handing over of responsibility by leprosy services, approval from the community, or financial appreciation in the form of a fee or at least the appropriate reimbursement of costs incurred.
- **Ownership:** Particularly in self-care and micro-finance groups, a strong sense of ownership helps to use peer support - and sometimes peer pressure! - to keep the activities running smoothly.

Based on interviews with Ms Rahmatia and Ms Fatmawati, members of the KUK management team. Interviews conducted by Kerstin Beise and Alkadri (PerMaTa), August 2017.

Nepal

Dhanusha Self-Help Groups Federation

As a registered local NGO, Dhanusha Self-Help Group Federation provides services beyond the borders of leprosy for communities as a whole

1. Nepal - Country background

Nepal is a landlocked Himalayan country with a population of nearly 29 million. It is among the least developed countries in the world. Improvements in poverty reduction and health care have been made in recent years, but diseases and malnutrition are still more prevalent in Nepal than in other countries of the region. For the majority of the 4 million people with disabilities in Nepal, and particularly for those with leprosy-related disabilities, social exclusion and poverty are part of their lives.

Leprosy elimination as a public health problem was reached at the national level in 2009, but around 3,000 new cases are still detected every year; 7.2% among them are children, and 3.7% have a visible disability at the time of diagnosis. The leprosy control program supports more than 100 self-care and self-help groups, and people affected by leprosy are encouraged to participate in leprosy services.

Situation in the area covered by Dhanusha Self-Help Groups (SHGs) Federation

Geographically, Nepal is divided into three zones: the Mountains, the Mid-hills and the Terai plains. People in many of the Terai districts live below the average poverty line. Dhanusha, with a population of around 800,000, is a district of Province No. 2, which is located in the Terai. The Terai accounts for 60% of new cases reported in Nepal (2009 data); of these, 13% already have visible disabilities at diagnosis. Strong stigma is still associated with leprosy.

2. Organizational background of the Dhanusha SHGs Federation

Dhanusha SHGs Federation is a registered local NGO consisting of 39 affiliated SHGs of people affected by leprosy, people with disabilities, and other marginalized people, formed in 2005 in the district of Dhanusha, South Nepal.

The SHGs in Dhanusha were formed as part of an INGO project started in 2002 based on the concept that when people affected by leprosy become agents of change in their communities, they will gain respect, thereby reducing stigma in these communities.

Initially, a number of people affected by leprosy received self-care training and were appointed as facilitators to develop self-care cells in their villages. They were supplied with lists of people affected by leprosy, whom they contacted and encouraged to join these cells. The members of the initial self-

care groups learned to take control of their impairments, thereby increasing their confidence. A year later they were provided with training to develop the cells into SHGs, where they started savings and income-generation activities. The SHGs invited other persons with disabilities and marginalized people to join. Together they expanded their activities into community empowerment projects for the benefit of their wider communities, for example by organizing literacy classes and infrastructure development.

When the Federation was established in 2005 and registered as a local NGO, it began with six affiliated SHGs, and 33 more groups joined during the year. New SHGs have to submit an application to the Federation and pay an initial NRs 2,000. A steering committee of 11 members is elected every five years. In 2017, the Federation had 760 members, with approximately 20 in each SHG; 67% of the Federation's members are people affected by leprosy and 19% are people with other disabilities, while 13% are other marginalized people. Since 2016, people with lymphatic filariasis have been included as well (1%). The INGO continues to provide motivation and occasional support.

3. Participation of the Dhanusha SHGs Federation in leprosy services

Not all SHGs associated in the Federation are involved in all leprosy services, but together they cover the entire range of services:

- Prevention of disabilities
- Referral of people with possible signs of leprosy
- Defaulter tracing and support
- Counselling
- Awareness-raising
- Rights advocacy
- Socioeconomic empowerment

The unique feature of the Dhanusha Federation, however, is their additional involvement in community empowerment for the benefit of other poor and marginalized people and the community as a whole.

4. The Dhanusha SHGs Federation at work

4.1. Prevention of disabilities

Persons affected by leprosy who embrace self-care as an important part of their lives will gain control over their impairments. As a result, they develop confidence and the conviction that **they can manage not only their wounds, but also their lives** by doing so.

How we work

Self-care is a key activity for our groups. The members affected by leprosy practice self-care weekly at our meetings and every day at home. Members who don't have impairments and those who are not affected by leprosy support and encourage us. As a consequence, today almost all ulcers are healed. Members who carelessly develop a new wound are fined by the group. Apart from self-care, we pay attention to the condition of footwear and other assistive or protective devices, and we help refer people with reactions or other emergencies to the hospital.

4.2. Referral of people with possible signs of leprosy

Early detection of new cases is vital to preventing disabilities and the further spread of the disease. People affected by leprosy can play an important role in this.

How we work

People in the communities who want to know if a skin problem they have could be leprosy visit our SHGs and ask us, before going to a health post. We are recognized for our leprosy work and our knowledge regarding the disease. **Many of our groups have become primary referral agents for leprosy, and people seek consultation from us.** If we find anyone who has possible signs of leprosy or skin problems during our daily activities, at the market, or at work, we advise and encourage them to go for an examination to a health post, the district health office, or an INGO leprosy service center.

Some of us also actively visit homes to look for those with signs. Usually we plan these activities in the group and discuss them with the INGO partner. Lately, as part of a new INGO project, we are now able to identify lymphatic filariasis in addition to leprosy

4.3. Home visits for defaulter support and counselling

Often people affected by leprosy have emotional, health, or family problems during the time of their leprosy treatment. Sometimes they refuse to take MDT regularly.

How we work

The local health post and district health staff contact us when they have a leprosy patient who has stopped taking MDT (a defaulter). We then go and try to support and motivate the person, so that he or she starts taking MDT again. Thanks to our activities, we now have a much lower default rate than in the past.

We have received training from the INGO in counselling, listening skills and problem solving, and support people affected by leprosy, including defaulters, either during group meetings or on home visits. We try to find out together what the problem is and then guide and encourage the person to find a solution. Counselling also includes the distribution of information about leprosy and other health issues.

4.4. Awareness-raising and advocacy

Misconceptions about leprosy are still widespread in Nepal, resulting in stigma and discrimination.

How we work

It is important for us that people understand what leprosy really is - people in the community, in the government, at health centers, and people affected by leprosy and their families themselves. We always seek opportunities to speak about leprosy with people we meet during our daily activities. In this way, the message is spread further and further. As a federation, we can effectively coordinate among the different SHGs to have them join activities at the district and even higher levels, including celebrations on World Leprosy Day, rallies, and mass awareness campaigns. Locally, our SHGs organize awareness-raising at schools. We also use **street drama**, which we prepare together with the INGO team, to convey our message in easy and fun ways. We also approach influential people in the communities by conducting "leprosy orientations," a short type of training about the facts of leprosy.

We interact with the local government not only to raise their awareness of our situation, but also to advocate our demands for equal rights and services. We participate in meetings at the village and district level to talk about rights, disability, and leprosy issues. As a result of our activities, many people affected by leprosy and people with disabilities have received disability cards for governmental support, and the government financially assists several of our activities



On the occasion of the 60th World Leprosy Day in Janakpur in 2013, the rally was organized by Dhanusha Self-Help Groups Federation supported by Lalgadh Leprosy Hospital and Services Center and the District Public Health Office. The slogan made by the Leprosy Control Division is “End discrimination and do rehabilitation. Our desire is a leprosy-free society.”



On the occasion of the 60th World Leprosy Day in Janakpur in 2013, Mr. Mainudin Dafali, a person affected by leprosy and President of Dhanusha Self-Help Groups Federation, standing at far right, gives a speech.

4.5. Socioeconomic and community empowerment

People affected by leprosy in Dhanusha have long been excluded from social life and economic development. As members of their SHGs, they are committed to creating better living conditions for their communities and for themselves.

How we work

All SHG members are saving money in their groups. This is the first step to economic empowerment. In addition, we provide loans to our members. We discuss applications together as a group, help plan the enterprise, and then provide the loan to a member, or to the group. So far, 600 members have benefitted from these loans and have started animal husbandry or other small businesses. Our loans have an annual interest rate of 12%, and we closely monitor the performance of the enterprise and repayments. In the early days we received funds for loans from the INGO, but now our SHGs have money available from repayments and interest, and we are supported with additional seed money by a number of government agencies.

*We did not stop at improving our own situation. In our communities, almost everybody is poor and **we want to contribute to our village development.** To identify possible goals, our SHGs meet with community members to discuss local issues and then seek solutions together. We have, for example, organized many adult literacy classes for illiterate women. We are active in improving sanitation, wells, roads, and housing. To successfully advocate for support, we draw on our good connections with local and district government units. In the beginning, the INGO guided us, but today we can do most things by ourselves.*



Self-help group members in Basaiya are seen here in 2015 discussing about saving, livelihood and repayment of loans.

5. Impact

- **Less impairment:** Hardly any group member affected by leprosy has wounds anymore, and other impairments have been reduced.
- **Social inclusion:** Through their engagement in community activities and realizing benefits for entire communities, people affected by leprosy have **become agents of change and have gained respect and acceptance**; they are now participating in village meetings, events, and religious activities. People come to their homes to ask for advice and invite them to join village committees. Stigma has been reduced considerably.
- **Enhanced economy:** As a result of the groups' activities and services, the economic situation of many families has improved. People have learned to read and write and are sending their children to school. With savings, loans, and vocational training, members can start small businesses and became increasingly financially independent. They now are able to get nutritious food and clothing, and even to buy land. Increased awareness and attention from the government has resulted in the distribution of disability cards and support for housing and disaster relief.
- **Participation in governance:** Members of the SHGs know their rights and are empowered and able to demand them. Their increased confidence allows group members to articulate their voice at all levels. Now their voices are heard: Three people affected by leprosy took part in elections at the local and national level and are now members of the respective parliaments.
- **Well-being in communities:** As a result of various health education activities organized by the SHGs, knowledge, attitude, and practice in communities has changed positively. People now wash their hands before eating and after using the toilet. The incidence of diarrhea, vomiting, and other diseases has been reduced. People more frequently go to a doctor instead of traditional healers. With their increased knowledge about the disease, people with possible signs of leprosy seek examination earlier.



SHG facilitators are learning to check blood pressure in order to contribute to optimal health of their community as a whole.

6. What motivates the Dhanusha SHGs Federation

The president of the Dhanusha SHGs Federation has experienced severe stigma in the past. He lost his job and, because of the disease and the impairments that developed as a consequence, became totally isolated. This **experience motivates** him to help find people with signs of leprosy and prevent disabilities through early treatment. Similarly, other members of the Federation feel driven by the wish to give people affected by leprosy a voice and help them to re-integrate in society on an equal basis with others.

“We were excluded from the community because of leprosy. The INGO provided us with skills and knowledge, and now we wish to use our new strengths to help others so that they do not suffer as we did.”

“We have suffered from leprosy and we understand what it is to be rejected. When we and our peers are economically empowered, we are independent and strong and better able to overcome stigma.”

7. Collaboration with the leprosy program and other stakeholders

The key partners of the Dhanusha SHGs Federation are the INGO and district and local governments. Because most activities the SHGs are engaged in require support from different sectors in society, networking is seen as a vital task by the Federation. For these reasons the Federation has built up relationships and mutual cooperation with governmental health services at different levels, local development and poverty-alleviation offices, women and child development agencies, the police, civic society organizations, organizations of people with disabilities, and many more.

The responses by these partners are very encouraging. The district health office, for example, understood the significance of the Federation and the contributions they are able to make to leprosy control, and started to support it. They are now jointly celebrating awareness-raising activities during World Leprosy Day and collaborating in leprosy orientation for key persons in the communities. Often, funds for the prevention of disabilities and income generation are provided by the district health offices.

8. Promoting factors

What factors made it possible for the Dhanusha SHGs Federation to participate successfully in leprosy services?

- **External guidance:** Intensive and proficient support and guidance by the INGO was crucial in the early years of the SHGs. This support has always been provided in empowering ways through sharing, practical learning (through activities like exposure visits to other groups), and active participation.
- **Self-care as a foundation:** By practicing self-care, the members developed increased confidence in their ability to manage their own lives. The energy created by this self-assurance is released and utilized to help others.
- **Community respect:** The SHGs provide services not only for themselves, but also for others in the community. The acknowledgement by neighbors and communities, local and district governments, the trust and respect of health post staff, and recognition and praise from the village authorities all provide the motivation to continue and expand their services.

- **High-profile activities:** Today, the Federation's public image has been further enhanced by high-profile activities like blood donations from persons affected by leprosy, by visits from international guests, and opportunities to speak at high-level national and international events.

9. Challenges

What are the difficulties of participating in leprosy services, and how can they be overcome?

- **Lack of capacities and motivation:** It has been a long journey for the members of the Federation to get where they are now. In the beginning, people were socially excluded and scared. They had no knowledge about leprosy and no awareness of their rights. They had no trust and often rejected the approaches of initial facilitators, who were also people affected by leprosy themselves. It was difficult to start the early self-care cells. Even once these cells were active, members still had no skills, knowledge or experience about self-care, and didn't believe that these practices could help in healing their wounds. They were poor and had to spend their time laboring; additionally, many were illiterate and not used to the concept of learning new skills.

The SHG facilitators relentlessly encouraged the new members to build up their capacities together. The INGO team provided vital motivation and support in this phase.

- **Internal issues:** Today, as mature groups, there still are challenges to overcome. As happens everywhere, the groups have **internal issues** to solve, problems between members, or family issues that delay their engagement in the groups. Members have obligations to work and families, which result in limited time available for the group. In addition, many of the members have permanent disabilities that occasionally impede their mobility. **Limited literacy** is another problem, and, as many members of the Federation's steering committee are Maithili speakers, language barriers in especially English and Nepali create further obstacles.

Members of the Federation are aware that full independence will take time to achieve. They are highly committed to solving challenges as they arise, and continue to work in line with the Federation's mission.

10. Support

What support did the Dhanusha SHG Federation and individual SHGs receive to make their work possible, and what support will be needed to continue working?

Significant support has been provided by the INGO, for example:

- **Capacity building** to become engaged in community empowerment in different sectors, including leprosy and lymphatic filariasis, mother and child health, sanitation, and rights for people with disabilities, women, and children
- **Funding** for meetings, community projects, seed money, and other items
- **Technical support and guidance** through regular supervision and monitoring

Today, some financial support from government agencies and the Federation's own funds is available for carrying out activities.

Looking toward the future, the Federation feels they still need motivational and technical support, training in a variety of aspects, and funding, and hopes for a continuous and increased commitment from the government.

11. Future plans

The Dhanusha SHGs Federation will continue working with the aim of full and equal inclusion of people affected by leprosy in society, and will support the government to achieve a Nepal that is free of leprosy.

In addition, the Federation has more plans and goals:

- They hope to set up a task force in each SHG to find new cases of leprosy at an early stage.
- They plan to conduct more WASH (water, sanitation, health) activities in each SHG.
- They want to raise funds to build their own district committee offices to run their activities and provide services effectively.
- They wish to publish a booklet about the SHG Federation.

12. Lessons learned

- **Self-care practice:** Self-care as the basic activity to control impairments and develop self-confidence should be part of every SHG.
- **Community empowerment beyond leprosy:** The uniqueness of the Dhanusha SHGs and their federation is their engagement in community empowerment. This has earned them immense respect and dignity, on which they were able to build and further develop their organization.
- **Inclusive groups:** Including people with other disabilities and other vulnerable people as members gives groups a broader perspective on life and the support of a wider network of supporting partners.
- **Comprehensive and well-funded initial guidance:**

Based on interviews with Mainudin Dafali, president of Dhanusha Self Help Groups Federation. Interviews conducted by Ravi Poudel, CBR Field Assistant, and Ramesh Kumar Choudhary, CBR Officer at LLHSC.

Annex - Rules of KUK

Kelompok USAHA KPD (KUK)

SCG Enterprise Group

1. This micro finance group is called “SCG Enterprise Group” (KUK), with its address at Ll. Dangko Ir.31.
2. The aim of KUK is to help its members to start and develop income-generating projects to raise their standard of living.
3. SCG members who actively practice self-care and attend meetings regularly can become KUK members. Membership cannot be transferred to another person.
4. All KUK members agree with the rules as set by KUK and described in this document.
5. All members have the right to:
 - Receive loans from KUK, as long as they fulfil all conditions
 - Attend KUK meetings
 - Use his/her voice at the KUK meetings
 - Bring forward opinions, suggestions, and advice for the further improvement of KUK
 - Know the current financial status of KUK
6. All members have the obligation to:
 - Save via the KUK system
 - Repay loans on time
 - Attend all meetings of KUK
 - Abide by all KUK rules
 - Keep up the good name of KUK
7. KUK meetings are conducted once a month, in the 4th week of the month, unless there are reasons to shift this date. The meeting is official if at least 50% of members attend. Decisions are made on the basis of a voice majority.

8. Management

- i. The KUK management consists of:
 - Chairman/woman
 - Vice chairman/woman
 - Secretary
 - Treasurer
- ii. The management is elected by the members with the condition that they are diligent, disciplined, honest and skilled, and that they know all rules of KUK.
- iii. The management is elected for a term of 3 years.
- iv. The members can stop the management at any time, if there is proof that the management:
 - Has engaged in fraud or otherwise harmed KUK
 - Has not abided by the KUK rules
 - Is no longer loyal to KUK
- v. Management staff can serve up to 2 terms.
- vi. If a member of the management staff stops serving before the end of a term, management will assign a temporary replacement.
- vii. Tasks and obligations of management:
 - To run the organization in line with the rules
 - To organize and run regular member meetings and management meetings
 - To carry out KUK administration, including
 - Registration books of members and management
 - Minutes of every meeting
 - Membership cards
 - Financial records and inventory records

9. Activities of KUK

- i. Providing loans to its members
- ii. Saving
- iii. Training
- iv. Monitoring and evaluation

Loan System KUK

1. Main objectives of providing loans to KUK members
 - Business: Business loans are given to members who own / intend to start a productive business (in goods or services).
 - Emergency: Emergency loans are given to members who experience an emergency (e.g. sudden illness, accident, school fees with deadline).
2. Amount of loan
 - Business: Minimum Rs. 500,000; maximum Rs. 3,000,000
 - Emergency: Maximum Rs. 500.000
3. Objective of the loan
 - i. The objective of a loan must be stated clearly in the proposal letter.
 - ii. Businesses may not be involved in speculative activities, may not be illegal or against moral standards, and may not harm the environment.
 - iii. Emergency loans are provided to help solve a problem.
 - iv. If previous loans have been misspent or misused, a new loan can (usually) not be given.
4. Mutual responsibility
 - i. Interest is 1% per total amount.
 - ii. Groups of 2-3 members form mutual responsibility groups and have to guarantee each other.
5. Collateral

Every loan has to be secured with collateral in the form of goods of higher value than the loan.
6. Repayments
 - Repayments have to be made within 1-12 months and can be made daily, weekly or monthly.
 - Daily repayments can be done in the afternoon, weekly repayments at Monday SCG meetings, monthly repayments from the 1st to the 10th of the month.
7. A loan from KUK has to be managed by the member together with his/her wife/husband/children.
8. It is not possible to get a loan as long as there are outstanding repayments from previous loans.
9. A loan cannot be transferred to another person.
10. Sanctions
 - Sanctions are stated in the loan agreement between the member and management.
 - If a member is late with repayments 1-2 times, he/she will be visited and warned that, if the repayment is late a 3rd time, the collateral will be taken by the KUK office.
 - If after one month the payment has still not been made, the management has the right to sell the collateral.



The International Federation of Anti-Leprosy Associations (ILEP)
www.ilepfederation.org

Sasakawa Memorial Health Foundation (SMHF)
www.smhf.or.jp/e