

Zero Leprosy Best Practices

Best Practice: *Self-help Group (SHG) Federation of over 100 SHGs to Successfully Address the Continuum of Care in Coordination with the National Leprosy Program towards Zero Leprosy*

Subthemes

- Operational capacity
 - Leadership and governance

Target Audience(s)

- Policy leaders
- Program managers
- Trainers
- Health staff
- Persons affected by leprosy
- Donors
- Other partners such as NTD NGOs

Key Messages

The *Bogura Federation* was established to unite over 100 self-help groups of persons affected by leprosy and other disadvantaged persons in Bogura District, Bangladesh. The Federation acts as a forum where self-help groups can discuss/advocate their rights, and it also assists group/member needs through income-generating activities, referral of new possible cases and morbidities, and access to social benefits. The number of leprosy cases identified has doubled since the Federation was created

Contributors

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Description of the Best Practice

Introduction

Bangladesh is providing good integration of multidrug therapy (MDT) in the health system and support during treatment. However, there is a lack of activities to address needs before diagnosis and after completion of treatment, leading to high grade-2 disability (G2D) cases and limited post-treatment care.

To improve this situation, Lepra Bangladesh initiated a process by working closely with people affected to form self-help groups (SHGs) aimed at reinforcing *inclusion* and strengthening the capacity of group members throughout the continuum of care. The process was mainly supported by Sasakawa Health Foundation (SHF), but also by the national government and local NGOs.

Best Practice: Self-help Group (SHG) Federation of over 100 SHGs to Successfully Address the Continuum of Care in Coordination with the National Leprosy Program towards Zero Leprosy

Zero Leprosy Best Practices

As an association that includes 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 but with other conditions (i.e., lymphatic filariasis [LF], other disabilities, acute poverty, etc.) participate in these activities as well, which helps to overcome exclusion.

Objectives and Methodology

The *Bogura Federation* was established to unite over 100 SHGs of persons affected by leprosy and other disadvantaged persons in Bogura District, Bangladesh. The Federation acts as a forum where SHGs can discuss their members' rights, and it assists and strengthens affiliated groups in their work. The Federation's activities are cross-cutting in addressing different aspects of leprosy control from early detection to capacity-building of the local health system. The Federation was formally recognized as a community-based organisation (CBO) and is now running independently.

Goal

To promote social, economic, political, moral, and cultural life through the empowerment of all the members of the organization and the people of the lower castes, especially the women, as well as contributing to the development of a progressive and dignified society framework established on fair principles through constructive activities.

Objectives

- a) Strengthen the capacity and leadership of existing SHGs
- b) Increase access/uptake of needed services through the continuum of care and available resources of public and private organisations
- c) Unite people with other disabilities and acute poverty status
- d) Alleviate the poverty status of SHG members

Inputs

- Group meetings to discuss yearly plans
- Capacity building of group members on self-care, community awareness on leprosy, and referral of suspect cases to the local clinic
- Commitment from beneficiaries. Everyone must agree to participate in each activity (their own self-care, awareness building, referral of suspect cases, loan disbursement, and return on time)
- Discussion with other partners/stakeholders who could contribute/support SHGs for capacity building and provide support on livelihood and advocacy with the government Social Welfare Department, Lepra, etc.
- Budget preparation/agreement
- Formation of a central team for supervision and monitoring, especially to supervise sub-district level Federation and SHGs and share plans

Best Practice: Self-help Group (SHG) Federation of over 100 SHGs to Successfully Address the Continuum of Care in Coordination with the National Leprosy Program towards Zero Leprosy

Zero Leprosy Best Practices

- Identification of suitable volunteer ‘Community Champions’ and the development of suitable health education materials
- Help in conducting need analysis and for developing new project proposals

Costs (Bangladeshi takas)

Example from “Amra Kori Project”

SN	Particulars	Unit	Unit cost	Total amount
1	Project Manager-1	12	50,000	600,000
2	Project Supervisor-1	12	30,000	360,000
3	Community Champion-12	12	3,000	432,000
4	Monthly monitoring with CC-17	12	6,000	72,000
5	Federation meeting at sub-district level-18	24	5,500	132,000
6	Federation meeting at district level-18	4	8,000	32,000
7	Travelling, food, and lodging–project staffs	12	6,000	72,000
8	Travelling, food, and lodging–Federation leaders	12	5,000	60,000
9	Capacity building–CC	1	15,000	15,000
10	Capacity building–Federation Leaders (15 person)	13	8,000	104,000
11	Livelihood training for group members (15 person)	24	8,000	192,000
12	Develop IEC materials	2	50,000	100,000
13	Admin cost (office rent, utilities, mobile & internet, repair & maintenance, etc.)	12	20,000	240,000
	Total			24,11,000

Bogura Federation has its own plan to distribute 15,00,000 to 20,00,000 Bangladeshi taka/year among 101 SHGs through 12 sub-district Federations. Currently, 101 SHGs have approximately 25,00,000 taka.

Implementation of Practice

Main Activities Included

- Recognition of early signs of leprosy and mobilization of possible cases for early detection
- Supporting defaulters during treatment period
- Preventing disabilities through peer support in self-care practice and morbidity management
- Counseling for people affected by leprosy and their families
- Socio-economic development / livelihood support
- Raising awareness of leprosy and available services in the community
- Acting as an advocacy forum to discuss members’ rights, access to socio-economic schemes

Best Practice: Self-help Group (SHG) Federation of over 100 SHGs to Successfully Address the Continuum of Care in Coordination with the National Leprosy Program towards Zero Leprosy

Zero Leprosy Best Practices

- Participating in general community health work, e.g., addressing malnutrition in the wider community, regular contact with the Social Welfare Department for providing disability grant/pension cards, etc.

When/ Where

The target area was Bogura district, Bangladesh. The “Bogura Federation” process started in 2011 with *inclusion*-related activities, and groups were formed in 2014. In 2015, the Federation was created at district and sub-district level with representatives of existing SHGs. In 2016, the Federation supported NLP in early detection and morbidity management. The Bogura Federation was formally recognized as a CBO in 2017 by the Social Welfare Department and is now running independently.

Implementers/ Collaborators and Roles

- 1,030 beneficiaries who are active members across existing 100 SHGs within the Bogura Federation
- Lepra Bangladesh: Main facilitator and funder
- Sasakawa Health Foundation: SHF has been supporting different projects from the beginning
- Government Health Department: Provides treatment and complication management after referral by SHG members, and also trains SHG members in leprosy diagnosis
- Government Agriculture Department/ Livestock Department/ Youth Development Department: Provides training on satellite projects
- Government Social Welfare Department: Support in building capacity about management and leadership, including access to social schemes
- BRAC Bangladesh (NGO): Support in building capacity about management and leadership
- NGO Forum (NGO): Support in building capacity about WASH
- Thengamara Mohila Sabuj Sangha (TMSS, a national NGO working for women development): Support in building capacity about management and leadership
- Food for the Hungry (NGO): Support in building capacity about management and leadership

Results—Outputs and Outcomes

A total of 100 SHGs with about 1,030 members (54% females, 48% males) have been formed since 2014. Since then, leprosy case detection has doubled in the district, suggesting many cases were previously undetected (see following table).

	2010	2011	2012	2013	2014	2015	2016	2017	2018
No. of new cases	105	46	83	75	62	150	110	156	125
No. of G2D	10	0	7	14	10	18	10	15	12
% of G2D	10	0	8	19	16	12	9	10	10

Source: NLP Bangladesh

Best Practice: Self-help Group (SHG) Federation of over 100 SHGs to Successfully Address the Continuum of Care in Coordination with the National Leprosy Program towards Zero Leprosy

Zero Leprosy Best Practices

Of the total 3,925 suspect cases referred for leprosy diagnosis in Bogura District in 2018, 30% were referred by SHG members. Of the total 125 confirmed leprosy cases, 34% were referred by SHG members in the same district.

The Federation is also in regular communication with skilled leprosy health workers in the district. Via mobile phone, the health workers keep the Federation informed about defaulters. Federation members then visit the defaulters at home and talk about the importance of MDT as well as giving positive examples. In this way, SHG members helped 50 defaulters get back to treatment in 2018 in Bogura District.

Federation members visit SHGs and people's homes to explain and practice self-care together, and to help obtain assistive devices or protective footwear if needed. The affiliated SHGs also practice self-care together at their bi-weekly meetings. Counseling and discussing mental health and prejudice are a regular part of the meeting agenda. Together, the members discuss their problems and help each other share feelings, but also make sure everyone is aware of their rights and the availability of services.

Since 2014, the Federation's SHGs have supported 800 people in starting income-generating activities through its savings scheme. A total of 97 SHGs have opened bank accounts with seed money for these activities

Lessons Learned

Since the involvement of the Federation, leprosy case detection in the district has doubled. One of the key outcomes has been the transformation of the Federation's members, which further strengthens their participation in leprosy services. By gaining a better socio-economic outlook and being aware of their rights in society, they are now contributing to helping others.

This is not just a Federation of people affected by leprosy. A conscious decision was made to include people with disabilities as well as other marginalized members of society (e.g., divorced women). This turns the SHG into a platform to assemble, discuss problems and hopes, and make plans to realize these hopes. The Federation coordinates these aspirations and creates a united, strong voice through participation in local leprosy services and other community activities.

What did not work well?

Linkage with government high officials/administration persons was problematic because this process is a new area and requires special knowledge and skills. Bogura Federation is currently developing special knowledge and skill sets to work with different government departments in future.

Best Practice: Self-help Group (SHG) Federation of over 100 SHGs to Successfully Address the Continuum of Care in Coordination with the National Leprosy Program towards Zero Leprosy

Zero Leprosy Best Practices

What were the main challenges and how were these overcome?

- Formation of mixed SHGs. Inclusion in the mainstream of people affected with other NTDs and health conditions (LF, general disabilities and acute poverty)
- Accessibility for leprosy treatment (complication management) at government local hospital
- Regularity of meeting
- Maintenance of record register (documentation) at group level
- Installment of loan (loan recovery)
- Ensuring safety net support
- Function of sub-district federation

To overcome the above challenges, we engaged Community Champions for support, gave motivation and leadership skills, provided special nursing for weak groups, arranged cross-learning visits, provided close monitoring by the federation leaders, and developed good relations with local government and NGOs. Lepra staff also provide technical support for the above.

Replicability and Scalability

This project is certainly replicable in other areas that have SHGs. Lepra wants to replicate this in three neighboring districts in Bangladesh. However, the Federation needs initial motivation and capacity strengthening in order for these to become sustainable organisations. The Bogura Federation received management and leadership trainings, as well as technical support, to strengthen institutional capacity (e.g., in developing operational guidelines).

Factors and support that made it possible for the Federation to participate successfully across a number of different leprosy services include the following:

- Legal registration. Registered as a CBO, the Federation is now 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 Lepra has been essential in keeping motivation high and activities running.
- Experienced leadership. A qualified management team is vital when setting up a Federation. The leaders of the Federation at the district level have gained experience through their previous involvement in sub-district/village-based SHGs. From this engagement, they learned about the power of peer support and group activities.

The Federation still needs the facilitation of NGO partners to approach the government and access their support programs, mainly in the field of funding, income generation, and legal proceedings. Training opportunities are much desired, for example, in organisational strengthening, leadership, and livelihood development. The Federation hopes that capacity building in specific leprosy control activities such as identifying early signs of leprosy and participating in contact surveys will be increasingly provided by the leprosy program.

Best Practice: Self-help Group (SHG) Federation of over 100 SHGs to Successfully Address the Continuum of Care in Coordination with the National Leprosy Program towards Zero Leprosy

Zero Leprosy Best Practices

To ensure the above mentioned activities, the Federation needs technical persons and a partnership approach with an experienced organisation.

Bogura Federation requested additional technical support and also monitoring support through the designation of one Lepra staff for these activities during the next few years until they develop their own organisation capacity. Currently, Lepra Bangladesh is providing this support.

Conclusions

Although SHGs for people with leprosy exist in many places, it's the unification/organisation into a Federation accepted by the government as a CBO that makes the Bogura example special. The Federation has established a relationship of mutual respect and close collaboration with the local health system and leprosy control program.

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 are important elements in the Federation's agenda. Members not affected by leprosy participate in these activities as well, which can help to overcome exclusion.

The Federation has demonstrated itself to be relevant through the entire continuum of care—from mobilizing patients for diagnosis and complication management, to peer support in the management of morbidities, and to advocacy and inclusion. Moreover, the Federation has also demonstrated to have an impact on the members' financial situation through livelihood- and seed-fund related projects. It has also been involved in the broader health status of its communities.

For more recommendations, see “[Replicability and Scalability](#)” section above.

Further Readings

Results were published on page 6 of the following report:

Good practices in strengthening participation of persons affected by leprosy in leprosy services. Geneva and Tokyo: ILEP and Sasakawa Memorial Health Foundation, 2018. <https://www.ilepfederation.org/wp-content/uploads/2018/08/5th-201805GoodPractices.pdf>

This booklet includes eight cases from seven countries on strengthening participation of persons affected by leprosy in leprosy services.