

Self-help group: A model for integrated care and socio-economic rehabilitation for People affected by Neglected Tropical Diseases

BACKGROUND

Globally, over 1 billion people in tropical and sub-tropical countries are affected by Neglected Tropical Diseases (NTDs), prevalent in settings marked by poverty and poor living conditions. Nepal, among the ten endemic countries, faces challenges with diseases like leprosy and lymphatic filariasis, leading to physical impairments and societal exclusion. The co-endemicity of these skin NTDs calls for integrated management, especially in resource-scarce areas. Kapilvastu, a highly endemic district in Nepal, reported 621 new cases of leprosy with a prevalence rate of 2.4 per 10,000 population in FY2079/80. Additionally, 2,746 cases of lymphatic filariasis were reported from Morbidity Management and Disability Prevention (MMDP) survey in Kapilvastu in FY2080/81. These statistics underscore the pressing need for comprehensive strategies to address and manage NTDs in regions like Kapilvastu.

SELF-HELP GROUPS

Self-Help Group is an approach to address the holistic needs of people affected by neglected tropical diseases (specifically leprosy and lymphatic filariasis), disabilities, and poverty to ensure that these individuals can navigate life with dignity and purpose. Along with performing self-care practices, members in the group engage in activities to foster emotional support, skill-building, and collaborative efforts to tackle the common hurdles that these members face. At present, there are 39 self-help groups with 534 members across Kapilvastu district. Each member undergoes a comprehensive three-day training program covering self-care for disability prevention and management, reducing vulnerabilities related to leprosy and lymphatic filariasis, group management, meeting procedures, and maximizing the benefits derived from the group. Empowered by the training and additional support, members conduct regular monthly meetings, practice self-care, review their progress, and strategize for upcoming tasks. They attest that these activities not only enhance self-confidence and inspire hope but also significantly contribute to elevating their dignity in life.

OBJECTIVE OF SELF-HELP GROUP

Improve access to basic rights and services

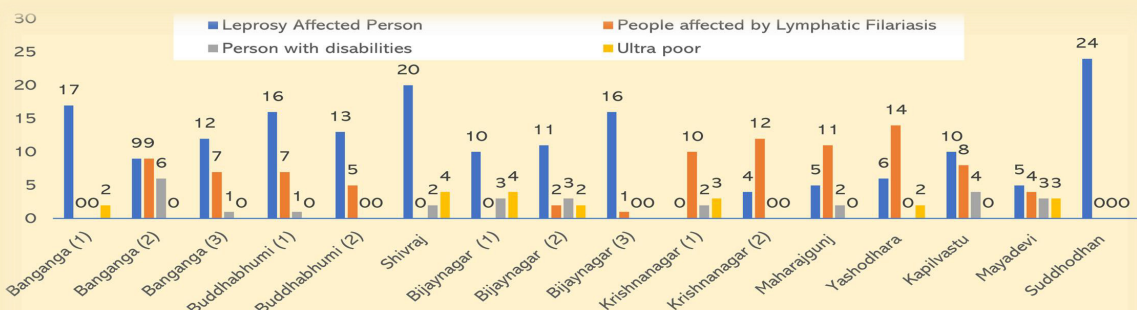
Prevention and management of disability through self-care

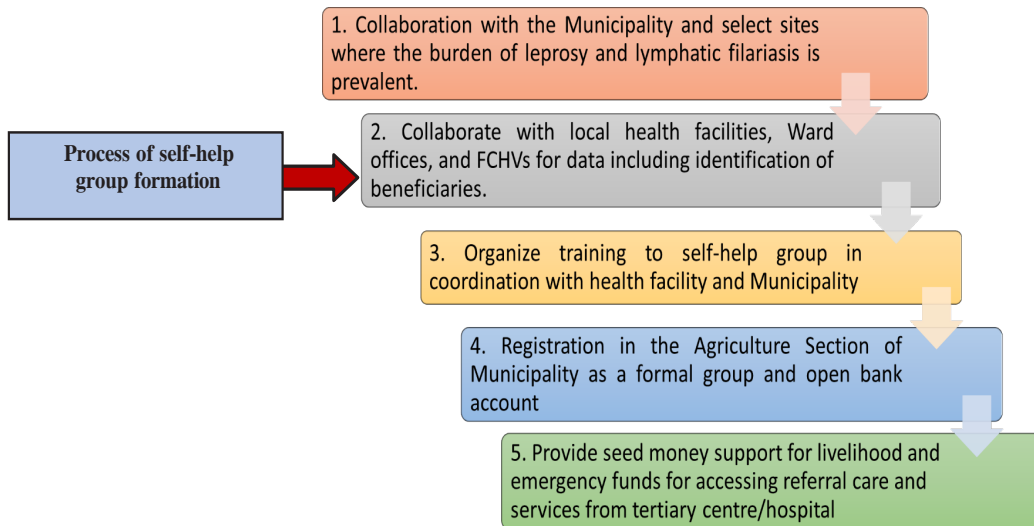
Reduce stigma and discrimination by provision of social support from community and family

Promote quality life and well being by engaging in income generation activity

Advocacy for creating enabling environment for NTDs affected people

COMPOSITION OF SELF-HELP GROUP IN KAPILVASTU





Mobilization of Self-Help Group

At Community level

- ⇒ Monthly meeting of the group by the project's field empowerment supervisor
- ⇒ Practice self-care during the meeting and discuss health issues like NTDs, WASH, and other health topics.
- ⇒ Discuss seed fund mobilization and carry out monthly savings.

At Household level

- ⇒ Role model self-help group members visit SHG members and newly diagnosed cases to counsel on self-care and encourage affected person/family members to do it routinely.
- ⇒ Role model self-help group members mobilized during national Campaign to sensitize the community to behavior change



Self help group members of Motipur gathered for their monthly meeting



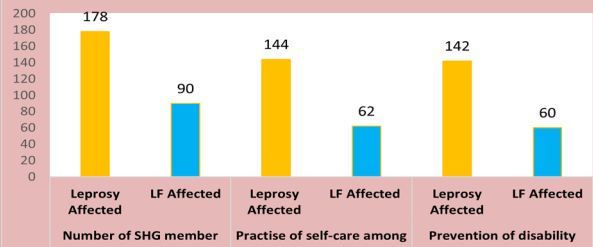
Santola Pandey, role model of Bithuwa self-help group disseminate information on self-care using flipchart during her household visit.

OBJECTIVE OF SELF-HELPGROUP

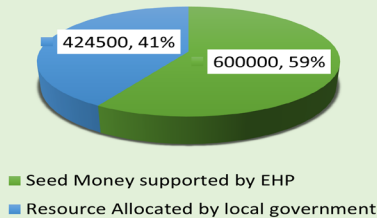
A. PREVENTION AND MANAGEMENT OF DISABILITY

- ⇒ The project trained total 268 people affected by leprosy and lymphatic filariasis about self-care.
- ⇒ Among total trained self-help group member, 144 leprosy affected person and 62 LF affected practiced self-care at home in regular basis
- ⇒ Due to regular self-care, 142 leprosy affected self-help group members were prevented from developing any kind of disability like ulcer, wound, deformity while there was reduction in swelling of limbs in 60 LF affected members

Prevention of disability among self-help group members



Composition of fund support for income generation in self-help group

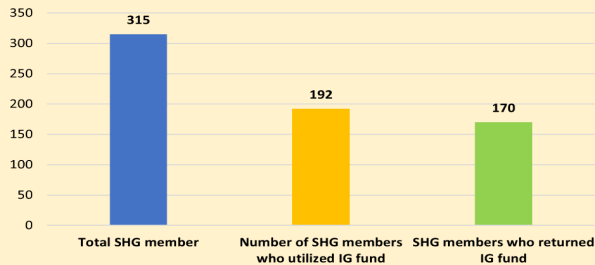


- ⇒ Project supported NRs 600,000 to 12 self-help groups as seed money for income generation.
- ⇒ 5 local governments (Shibraj, Budhabhumi, Maharajgunj, Suddhodhan and Badganga) have allocated NR 424,500 which accounts for 41% of the total IG fund of self-help groups in Kapilvastu.

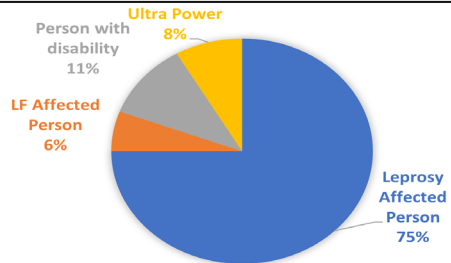
60.9% (192) has utilized the seed money for vegetable, farming, poultry, grocery, shop and animal husbandry.

88.5% users of seed money have returned it back to group.

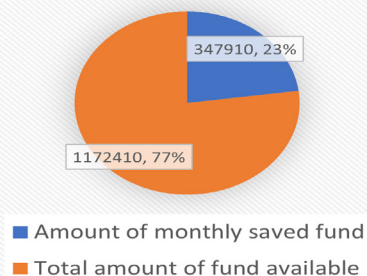
Utilization of seed money for income generation



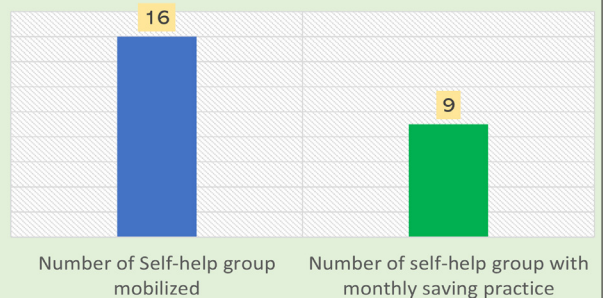
UTILIZATION OF IG FUND BY TYPE OF SHG MEMBER



Proportion of fund generated through monthly saving in self-help group



Practice of Monthly Saving in self-help group



Nine self-help groups have generated total amount of NRs 34,791 through monthly saving which contributes 23% of overall fund available in those groups.

Stories of change shared by self-help group members

Chaituram Tharu, a 25-year-old youth affected by leprosy, heads a small family of six. As the primary provider, he faced depression due to a lack of employment opportunities in his locality, struggling to fulfill his familial responsibilities. Feeling disconnected from social life, he found a turning point by joining a self-help group. With the seed money received, he ventured into vegetable farming, attracting local community members and retailers to purchase his produce. Now, he is warmly embraced by his family and community, a transformation he deemed impossible earlier. Chaituram aims to share his knowledge and skills with other group members, contributing to their empowerment.



Garbha Tharu, a 62-year-old individual affected by lymphatic filariasis (LF), spent over a decade seeking treatment for the swelling in his legs, experiencing persistent pain. Upon joining the Motipur self-help group, he underwent training on managing his swollen limb, initiating a transformative self-care routine. Today, he can walk and perform daily activities comfortably. Serving as a role model, Garbha not only counsels and motivates fellow group members but also extends support to others affected by lymphatic filariasis at the community level.



Indrawati Yadav, a leprosy-affected individual for the past seven years, faced discrimination from her community and family, leading to her confinement in a cowshed after diagnosis. In 2019, the Essential Health Project (EHP) brought together individuals affected by Neglected Tropical Diseases (NTDs) and established a self-help group, of which Indrawati became a member. The EHP provided the group with a 3-day self-care training and a financial support of Rs. 70,000 for income generation. Indrawati invested Rs. 20,000 from the amount in purchasing two goats, which eventually gave birth to five kids. After selling them, she earned Rs. 70,000. The goats continued to reproduce, providing a sustainable source of income. Indrawati utilized the earnings to meet essential needs such as clothing, food, books, school fees, and more for her children. With a smile, she shared, "Despite the challenges of leprosy, I've emerged as a leader in the village. Thanks to the Essential Health Project by Kalika Self Reliance Social Center in partnership with Fairmed Foundation Nepal, I've transitioned from a cowshed to this improved life, earning money and meeting our basic needs through a home-based business."

Shoharatiya Tharu, a 62-year-old individual affected by lymphatic filariasis (LF), dedicated 40 years to various treatments, seeking relief from the disease and spending significant amounts of money without success. Despite consulting traditional healers, her condition persisted. In 2020, Shoharatiya joined the Dubiya Self-Help Group (SHG) and underwent a 3-day training on self-care. Committing to regular self-care practices at home, she has not experienced any attacks in the past three years, and the swelling in her legs has decreased from 18.5 to 16.0. Shoharatiya has become a role model, counseling others in the community to adhere to proper medication and embrace consistent self-care practices. She emphasizes the crucial role of regular self-care in preventing further complications and disabilities in her life.



Himlal Ghimire, a dedicated health worker at Motipur Health Post, has served in the field for over 25 years. Initially relying on signs and symptoms for healthcare provision, his approach transformed after receiving training in Neglected Tropical Diseases (NTDs). In 2020, the Essential Health Project formed a self-help group, and Himlal took the initiative to train the Motipur Self-Help Group. Following the training, the group initiated regular monthly meetings, with Himlal providing ongoing health education and reorientation on self-care during his visits. He emphasizes the crucial role of regular self-care in preventing complications and disabilities among the group members. Himlal advocates that medicine alone is not the sole solution to combat NTDs; regular self-care, performed at least twice a day, is equally vital. He urges all individuals affected by NTDs to adhere to proper medication and incorporate consistent self-care practices into their daily routines.

Health Project. Reflecting on the impact, he shared, "The training significantly enhanced my knowledge and behavior. Previously, our focus on leprosy was mainly on administering a full dose of medicine, with limited emphasis on follow-up care post-RFT. The training enlightened us on the importance of regular follow-ups and teaching self-care, crucial for preventing disability."

Yogya Prasad emphasized the role of community dialogue in addressing the stigma associated with NTDs. Through consistent discussions with local government stakeholders, they have heightened their concern for these diseases, allocating budgets for screening suspected cases and supporting self-help groups to reduce stigma and uplift the living standards of the community.

In conclusion, Yogya Prasad stated, "Training health workers on NTDs is an investment in the well-being of communities, as their expertise becomes a powerful force in breaking the cycle of neglected tropical diseases."



SN	Name of Self Help Group	Contact No.	Address
1	Banganga Swayam Herchaha Krishak Samuha	9843687259	Banganga Mun. ward no. 3 & 4
2	Motipur Swayam Herchaha Krishak Samuha	9807403314	Banganga Mun. ward no. 7 & 8
3	Ramjanaki Swayam Herchaha Samuha	9816487563	Banganga-5, Kopawa
4	Dubiya Swayam Herchaha Krishak Samuha	9844747310	Buddhabhumi-3, Dubiya
5	Hariarpur Swayam Herchaha Krishak Samuha	986655401	Buddhabhumi- 8, Hariarpur
6	Chamarbhajiya Swayam Herchaha Krishak Samuha	9807402229	Shivraj-9, Chamarbojiya
7	Magarghatta Swayam Herchaha Krishak Samuha	9815488635	Bijaynagar-2, Magarghatta
8	Jauwabairath Swayam Herchaha Krishak Samuha	9869787672	Bijaynagar-1, Jauwabairath
9	Ganeshpur Swayam Herchaha Samuha	9812927603	Bijaynagar-7, Ganeshpur
10	Bidhyanagar Swayam Herchaha Krishak Samuha	9807457564	Krishnanagar-10, Bidhyanagar
11	Bhagwanpur Swayam Herchaha Sauha		Krishnanagar-9, Bhagwanpur
12	Maharajgunj Swayam Herchaha Krishak Samuha	9811997920	Maharajgunj-2,3,1,9
13	Rangapur Swayam Herchaha Krishak Samuha	9806928423	Yashodhara-6, Rangapur
14	Dohani Swayam Herchaha Krishak Samuha	9702369925	Kapilvastu-8, Dohani
15	Baluhawa Swayam Herchaha Krishak Samuha	9824476692	Mayadevi-5, Baluhawa
16	Bithuwa Swayam Herchaha Krishak Samuha	9818504329	Suddhodhan-4, Madhunagara

Few relevant photos of activities undertaken by self-help group



Visit from MoHP, Lumbini Province to self-help group of Bijaynagar Rural Municipality



Self-help group effort in addressing stigma in community published in a national newspaper.



Orientation program to self-help group on health-related rights and service provisioned by local government



Brijal Gosai role model of Rangapur self-help group promoting self-care among members



Self care demonstration by EHP staff



Income generation activities done by SHG



POID Clinic



Joint visit from FM & Demian Foundation to Self Help Group



Joint visit from FM & ILEP to Self Help Group



Self care kit supported to SHG



Self care demonstration during FCHVs Training



Self care corner visited from FM & ILEP

Contact
Essential Health Project
 Kalika Self-Reliance Social Centre
 Phone: 076560282 Email: kssc@ntc.net.np Website: ksscnepal.org.np



कालिका
 स्वावलम्बन सामाजिक केन्द्र