

Issues

People affected by leprosy have been displaced from their original communities and now reside in colonies and communities within the Kathmandu Valley. They have faced a multitude of challenges. These challenges include, substandard housing conditions, inadequate hygiene facilities, limited mobility due to the risk of physical damage, recurring ulcers, and deformities. They struggle with mental well-being issues, self-esteem and employability.

Perceptions of the wider community towards these individuals have not been supportive for their growth and well-being. Insufficient knowledge about leprosy, its causes, modes of transmission, and its socioeconomic impact led to rejection, stigmatization, discrimination, and alienation in multiple aspects of their lives. This includes facing barriers in healthcare, education, income generation, employment opportunities, and a lack of access to local and government resources and support.



Actions taken to solve the issues

NLAWA implemented a widespread awareness initiative on leprosy in 7 government schools and colleges, targeting students as 'agents of change' and creating a multiplier effect to deliver factual information about leprosy and to challenge traditional beliefs, fostering a positive atmosphere.

NLAWA initiated a collective campaign of lobbying, advocacy, and networking with various local entities including municipalities, ward offices, Leprosy Control and Disability Management Section (LCDMS), local health posts, schools, colleges, National Federation of Disabled Nepal (NFDN), and relevant government departments. The purpose was to raise awareness about the plight of people affected by leprosy and their hardships. This effort involved direct meetings, active participation in public programs, commemorating specific days, and engaging in planning and preparatory meetings organized by local, federal, and national government departments concerned with the issue.

NLAWA lobbied and partnered with other community stakeholders, such as IDEA Nepal, Sarangkot Foundation, and the local municipality, to provide emergency aid, medical assistance, and relief support to people affected by leprosy during humanitarian emergencies and crises such as COVID-19, earthquakes, and lockdowns.



Actions taken to solve the issues (cont.)

We have organized rallies, interactive sessions, and events in collaboration with national and international organizations, such as IDEA Nepal, the Leprosy Mission Nepal, NFD-N provincial committee, OPDs and the municipality, to commemorate Dignity Day, Disability Day, and World Leprosy Day. These initiatives aim to raise awareness about leprosy and eliminate the stigma associated with the disease. We foster meaningful interactions and engage with diverse stakeholders to promote understanding, empathy, and support for individuals affected by leprosy.

We have established an affiliation with the National Federation of Disabled Nepal to collectively advocate and lobby for the integration of leprosy-related concerns with other disabilities. Our aim is to highlight the importance of treating leprosy as a regular health issue and promote inclusivity and equal rights for individuals affected by the disease. We can combine our efforts to raise awareness, eliminate discrimination, and ensure that people living with leprosy are fully included in society, alongside individuals with other disabilities.

An allocated budget has been set by the Nepal Government (i.e. Provincial Social Development Ministry) to implement an economic empowerment program, specifically designed for 15 women affected by leprosy residing in the Lipikot leprosy community. As part of this initiative, we organized an advanced hand knitting training program to enhance their skills and provide them with opportunities for sustainable income generation. We seek to empower these women and enable them to achieve financial independence and improved livelihoods for a decent and better life.



Results

The perception of community members is changing towards people affected by leprosy, proven by community member participation in leprosy related programs inside the rehabilitation centers.

Local and wider community members are accepting the members of the colonies and people affected by leprosy, proven by the participation of the leprosy affected people in different social events in the communities.

People that have experienced Hansen's disease are participating in government-led programs, and different committees with different roles and initiatives thanks to the support from local governments and other stakeholders.

People affected by leprosy have started actively participating in orientation sessions, rallies, and programs alongside individuals with other disabilities, adopting an integrated approach.



Results...

The social status of people affected by leprosy has improved thanks to the increased interaction and participation between leprosy affected members, other people with disabilities, community members, local governments, business owners and other stakeholders in community activities.

The government has allocated a budget specifically set for the regular provision of self-care materials and medicine, an LPO advocacy has been obtained in order to prevent further disability issues resulting from leprosy. This dedicated support plays a vital role in halting further deterioration and disability, while simultaneously fostering enhanced health conditions.

The local government is requesting that the Leprosy People Organization (LPO) submit proposals for the allocation of budget towards specific activities.



Lessons learnt

Regular engaging of LPO for the budgetary provision and advocacy during the planning process with the government has led to the development of a sense of ownership and internalization of the leprosy issues.

Awareness programs run through schools and colleges can bring the multiplier and cascading effect to recognize leprosy as an on-going issue and can generate empathy of the younger generation, which can in turn help minimize further stigmatization and discrimination.

Collaborative and inclusive approaches of the government, Leprosy People Organizations (LPOs) and Disabled People Organizations (DPOs) can help achieve sustainable changes and decrease dependence on external donor agencies, consequently easing the leprosy burden.

The sample project, with the support of the government, holds the potential to make a meaningful impact on the wider community. By sharing the activities of the Leprosy People Organization (LPO), valuable insights and lessons can be gained by government units in various areas.



Lessons learnt...

- Intensive and focused leadership and regular engagements with the local government of LPO can promote and establish regular access to government resources.
- Regular interactions between the leprosy affected community and different levels of government contribute to a development of confidence in leprosy affected people, which empowers them to feel positive and recognize that they are an integral part of the community, and eventually such perceptions can help them overcome other socioeconomic challenges.
- Engaging representatives of the Leprosy Persons Organization (LPO) or individuals affected by leprosy in regular interactions with government entities not only creates valuable opportunities for leadership development but also facilitates political participation, which is crucial in establishing/recovering their rights.



What comes next

LAWA is taking the following actions:

- Enhancing engagement with the central government and looking for more collaboration with the National Federation of Disabled Nepal. Together, LAWA facilitates the inclusion of individuals affected by leprosy across the country through the general disability program, which includes the abolition of discriminatory laws and advocacy for improved policies and social security schemes
- Seeking more investment in the area of mental health by engaging in research, providing mental health support, advocating to support leprosy affected elderly individuals, and creating more employment and business opportunities for people affected by leprosy
- Looking to run more awareness raising activities in partnership and collaboration with other OPDs, LPOs, PABSON, NPABSON and government-run schools to reach the younger generation, passing on accurate information about leprosy, dispelling negative myths about leprosy, and creating a wider empathetic environment
- Collaborating with like-minded organizations to create a greater synergy especially by integrating its awareness and advocacy activities with other training (business and mental health) and outreach programs
- Prioritizing active participation in the government policy process, creating regular budget advocacy for the inclusive program design, and continuing our best efforts in engaging with governments at a higher level
- Advocating and seeking a stronger implementation of UNCRPD and SDGs in all the levels both in the public and private sectors
- Taking an initiative in establishing network committees in each of the seven provinces in Nepal, which could result in more active involvement in the government's budgetary process to undertake diversified supportive programs, tailored especially to assist individuals affected by leprosy
- Lawa has also been strengthening the collaboration with other humanitarian organizations to establish LAWA as a recognized humanitarian organization in Nepal and beyond