

(1) Issues to Be Tackled

1. Stigma and discrimination against individuals affected by leprosy due to misconceptions and lack of awareness.
2. Deprivation of rights experienced by individuals affected by Hansen's disease and its consequences.
3. Lack of accessible and suitable medical treatment for Hansen's disease in Ethiopia.
4. Majority of individuals affected by Hansen's disease reside in slum areas or leprosy colony settlements across Ethiopia, often located far from urban centers and lacking proper infrastructure and educational opportunities.
5. The isolated living conditions in these areas and colony settlements have led to misconceptions that leprosy is a curse, an inheritable, and an incurable disease.
6. Many of these individuals face financial vulnerability, relying on begging as their main source of income.

(2) Settlements Colony



KoKosa settlements colony



Addis Tesfay Hiowt settlements colony

(3) Measures Taken to Solve the Issues

- Promoting solidarity among individuals affected by Hansen's disease to address issues, break the barriers of stigma and discrimination, and reclaim their rights.
- In Addis Ababa, individuals affected by Hansen's disease gathered at the hospital to demand improved medical treatment.
- The establishment of the Addis Ababa Leprosy Association aimed to advocate for proper medical care, rehabilitation, and rights of individuals affected by Hansen's disease, leading to the formation of the Ethiopian National Association of Persons Affected by Leprosy. This national association supports individuals and their families across Ethiopia, addressing various challenges.
- The Ethiopian National Association plays a crucial role in raising the voices of individuals affected by Hansen's disease, becoming a member of the Ethiopian National Association of Disabilities and actively networking with government bodies (such as the Ministry of Labor and Social Affairs, Ministry of Health), as well as donor organizations like Sasakawa Health Foundation, The Leprosy Mission New Zealand, and German Leprosy and TB Relief Association. They focus on capacity building, rehabilitation, and addressing discrimination and rights violations.
- An annual general assembly brings together branch members from across the country, facilitating discussions, problem-solving, and knowledge-sharing among the branch associations.

(4) Achievement

- The establishment of branch associations has been a gradual process. Initially, seven regional associations were formed, which subsequently fostered the creation of approximately 72 branch associations spread throughout Ethiopia.
- Efforts have been made to raise awareness and reduce stigmatization and misconceptions surrounding leprosy. This involves the population at large, as well as those personally affected by the disease. An annual event, World Leprosy Day, emphasizes the ongoing relevance of the disease with the motto, "Don't Forget Leprosy."
- Rehabilitation efforts are continually expanding, including income-generating activities, flour milling, and emergency support, all provided to individuals affected by leprosy.
- Educational opportunities have been made accessible to individuals living with Hansen's disease.
- Support from both government entities and donors has enabled those affected by leprosy to exercise their rights, strengthen their associations, and build both financial and human capital.
- The practice of networking with partners serves to amplify the voices of those affected by leprosy. This includes their representation at global meetings and congresses, ensuring their perspectives and needs are heard.



(5) Achievement

- In 2011, ENAPAL requested land from the Ethiopian government. After six years, the government granted a 1,500-square-meter plot for their new head office building.
- ENAPAL secured financial support for construction expenses from organizations like the Sasakawa Health Foundation.
- Despite facing obstacles such as the COVID-19 pandemic and soaring construction costs, ENAPAL successfully completed their building in 2022, representing dignity for individuals affected by leprosy.



(6) Lessons Learnt

- Providing employment opportunities empowers individuals affected by Hansen's disease, reducing dependence on begging and enhancing their quality of life.
- Establishing an association is vital to combat stigma and discrimination faced by those with Hansen's disease, promoting financial independence through employment and income-generating activities.
- After six years of government lobbying, the Ethiopian National Association of Persons Affected by Leprosy obtained land and built a five-story building, highlighting the value of persistent advocacy for positive results.



Ulcer care clinic



Income generating

(7) Lessons Learnt

- Through strong advocacy, ENAPAL successfully persuaded the government to provide free land in the capital. With support from the Sasakawa Health Foundation, we constructed our national office. The building is now leased to other organizations, generating revenue to sustain our movement.
- Associations possess the capacity to address the issues faced by individuals affected by leprosy, alleviating problems and reducing stigma and discrimination.
- As a result, we, persons affected by Hansen's disease, have gained valuable insights that enable us to extend assistance to people with disabilities in Ethiopia and other African countries, empowering them to lead dignified lives.



(8)What Comes Next

- To bring the attention of the government and nongovernment bodies to bring policy and strategically change to end stigma and discrimination of Persons Affected by Leprosy in Ethiopia.
- To achieve financial independence and stability, currently leasing the building to maximize rental income while planning to move their headquarters there in the future.
- Networking with partners over sea to raise voices of persons affected by Hansen's disease in world wide, taking advantage of international congresses and meetings.

