



Advancing Leprosy and Disadvantaged Peoples Opportunities Society (ALO)

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website:



Presented by



1 Needs Assessment 1 Overview

Treatment barriers and mental health situation of persons affected by leprosy from a human rights perspective in Bangladesh.

Methods :

- A qualitative approach
- 1 FGD with ALO leaders and members
- 4 FGDs persons affected by leprosy
- 6 Case story of persons affected by leprosy
- 5 KIs with leprosy-focused NGO representatives
- 5 KIs with government health officials

People Reached:

- 45 persons affected by leprosy - 1 male child, 1 female teenager, 18 female adults, 25 male adults
- 11 family members of persons affected - 10 females, 1 male
- 16 staff (CRP) of organizations of persons affected by leprosy - 7 females, 9 males
- 5 representatives from leprosy-focused NGOs - 1 female, 4 males
- 5 Government health officials - 1 female, 4 males



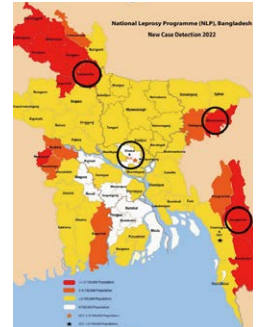
5 Organization Needs Assessment

Methods :

- A qualitative approach
- 1 FGD with ALO leaders and members
- 4 FGDs with leaders, members and staff of federation (OPLD)
- 5 with leprosy-focused NGO representatives

People Reached:

- 6 Executive Committee Members, including the Chairman of ALO
- 50 Executive Committee Members and General Members of organizations of persons affected by leprosy (OPLD/Federation)
- 16 staff (CRP) of organizations of persons affected by leprosy
- 5 representatives from leprosy-focused NGOs – 2 Project Managers, 1 Project In-charge, 1 Area Development Officer, and 1 Community Resource Person



2 Treatment Barriers During and After MDT

Treatment Barriers during MDT

Key Findings and Learning:

- 60% referred availability and accessibility of MDT at Sub-district Health Complexes (UHCs) needs to be improved.
- In areas where no leprosy-focused NGO, cases often go undetected, and MDT is not stocked at health facilities.
- Self-reported suspects are referred to major cities for confirmation and treatment.
- Patients living in remote areas face geographic and financial barriers, as MDT is only available at UHCs.
- The designated government leprosy staff (TLCA) is not always present at health facilities.
- The number of TLCAs is gradually reducing, and the government has not initiated new recruitment.
- In NGO supported health facilities, MDT is often distributed only on specific days.
- In some areas, there is a shortage of child-dose MDT, which is sometimes entirely unavailable.
- Lack of field-level follow-up by government health staff leaves patients unsupported.
- Absence of counselling support at the time of diagnosis.

Treatment Barriers after MDT

Key Findings and Learning:

- 60% reported access to healthcare for other medical needs requires improvement.
- Many hospitals are reluctant to admit persons with a history of leprosy, particularly those with visible leprosy-related disabilities, even for unrelated health issues.
- Health personnel often maintain distance when treating individuals with a history of leprosy or sometimes refer them to specialized leprosy hospitals, even for health issues unrelated to leprosy, reflecting persistent stigma.
- As most persons affected by leprosy come from low-income backgrounds, they often can't afford treatment for other health issues in private hospitals, worsening exclusion and delaying necessary medical care.



6 Key Gaps

- Limited support for addressing members' needs, including livelihood opportunities (disability friendly and climate-resilient), skill development, educational support, counselling and primary complications care.
- Absence of regular staff (CRP) in federations hampering daily operations and effective facilitation of SHGs.
- Limited funding opportunities (e.g., only TLM and SHF).
- Insufficient capital to sustain the organizations and the savings and credit programme.
- Weak second-line and young leadership.
- Limited capacity in drafting project proposals and reports due to poor writing skills.
- Absence of essential organizational policies and guidelines.
- All organizations do not have a permanent office space/building.
- Lack of leadership, financial management, organizational management, advocacy, and project implementation skills.

Opportunities

- Contribute to the Zero Leprosy goal through active involvement in new case detection, referrals, primary complications care, community awareness, and advocacy.
- Mobilize resources from diverse sources such as national and international donors, government programs, corporate social responsibility (CSR) funds, and individual donors.
- Strengthen ALO's identity and reputation as a recognized and impactful national NGO.
- Develop member federations into sustainable people's organizations that address members' needs.
- Strengthen networks and partnerships with other like-minded NGOs, government bodies, and private organizations.
- Support members in accessing social safety net services and livelihood opportunities.
- Serve as an information hub for members.
- Enhance financial sustainability by the optimum use of existing capital and strengthening self-help savings and credit programme.

3 Access to Leprosy-related Complication Services

Key Findings and Learning:

- 100% reported access to appropriate healthcare services for leprosy-related complications at government health facilities requires significant improvement and integration.
- Currently, these services are not available at all UHCs, district hospitals, or medical college hospitals.
- Specialized care for leprosy complications is available only in NGO-managed facilities.
- In most cases, government health staff refer patients with complications to both government and NGO-run leprosy hospitals.
- The three government leprosy hospitals offer minimal services and lack capacity to manage complex cases, often referring them to NGO hospitals.
- Medical college hospitals, despite having technical capacity, do not offer services for leprosy complications.
- There is no government provision for assistive devices, particularly protective footwear, and the supply of such devices remains entirely dependent on NGO funding.

Mental Health Situation

Key Findings and Learning:

At Diagnosis

- All respondents agreed that individuals commonly experience severe mental distress, worsened by stigma, family reactions, and social misconceptions.
- Delayed diagnosis and resulting disability further harm mental well-being.
- Counselling is largely absent, leading some to hide their condition and seek MDT in secret.

During Treatment

- All respondents shared that mental health may improve with family and community support, though many still face isolation, rejection, and distress due to reactions or disability.

After Treatment

- Mental health improves for some, but stigma often persists, especially for those with visible disabilities.
- Employment discrimination and economic hardship further prolong mental distress and affect overall recovery.

7 Recommendations

- Securing NGO Bureau registration for ALO to independently apply for foreign funding and expand resource mobilization.
- Develop and strengthen human resources by building staff capacity and addressing existing gaps to ensure smooth operations and effective project implementation.
- Collaborate with The Leprosy Mission International – Bangladesh and other like-minded organizations in joint funding proposals to better address the needs of members.
- Position ALO and its members as key partners in the national leprosy program initiatives and a strong contributor to the Zero Leprosy goal.
- Provide technical support to member federations to help them grow into sustainable and self-reliant people's organizations.
- Enhance leadership and advocacy skills to influence policymakers and engage at local, national, and international levels.
- Promote environmentally friendly livelihood opportunities to support members while contributing to climate resilience and sustainability.



4 Recommendations

- Stronger government commitment, with improved integration of leprosy services into the public health system, especially complications care services.
- Integrating leprosy services into Community Clinics (CCs), such as screening, MDT distribution, follow-up, and community awareness, can ensure equitable and inclusive healthcare for persons affected by leprosy at the grassroots level.
- Capacity-building support for government health personnel to strengthen their ability to identify and manage leprosy-related complications at early or primary stages.
- Leprosy-focused NGOs and Organizations of persons affected by leprosy (OPLDs) can play a vital role in advocating with policymakers to integrate leprosy services within mainstream health care and ensure the rights and inclusion of persons affected by leprosy are recognized and upheld.
- International agencies like the WHO, Sasakawa Health Foundation, The Leprosy Mission International can support these initiatives.
- 100% of respondents emphasized the need for integrated active case-finding initiatives by the government to address these challenges and uphold the rights of persons affected by leprosy.



8 Wishlist Before Next ILC

- Inclusive and timely access to treatment facilities e.g. MDT and complications care for persons affected by leprosy.
- Persons affected by leprosy (members and beyond) and other eligible members have increased access to government safety net services.
- Mass people and health professionals have overcome stigma.
- Government is proactively involved in new case detection, especially in remote, climate-vulnerable and ethnic communities.
- ALO and its members are stronger and resourceful.
- International and national donors recognize and support leprosy people's organizations with funding.
- ALO and its member federation are actively engaged in zero leprosy initiatives.