



Association of People Affected by Leprosy (APAL)

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1 Listening to the Margins: Needs of Persons Affected Leprosy, reside in the deep grassroots

Inclusive and Participatory Methods

- Led by Affected
- Structured Surveys Across 4 States
- Focus on Lived Realities
- Direct Field Engagement
- Inclusive Demographics-
- Systematic Analysis in Excel



The assessment covered both rural and urban populations, with an emphasis on inclusivity across age and gender.

- Total Persons Affected: 800
- Men & Women (Adults): 485
- Children & Teenagers (Male & Female): 27
- Older People (Male & Female): 461



2 Main Results: Right to the Highest Standard of Physical and Mental Health

- 7 out of 10 people reported easy access to physical healthcare.
- 9 out of 10 people said there is no access to mental health services.
- Mental health is completely missing in most healthcare setups.
- Where healthcare is unavailable, people also face travel issues, no documents
- Many could not access care due to missing biometric ID or no medical certificate.
- Low awareness of government health schemes adds to exclusion.
- Physical care is available in parts, but mental health is ignored everywhere.
- Administrative problems block access for the most vulnerable.
- Mental health is a major human rights gap and needs urgent attention.



5 Methods Used for Needs Assessment 2

(Needs of Organizations of Persons Affected by Hansen's Disease)

- Group Discussions during Board Meetings
- One-to-One Personal Interviews (100 individuals)
- Two Virtual Zoom Meetings
- One Physical Board Meeting
- Inclusive approach to gather both collective and personal insights



Participation in the Needs Assessment

- 100 total participants from APAL
 - 30 State Coordinators
 - 52 Colony Leaders
 - 10 Volunteers
 - 8 Executive Members
- Diverse representation: strategic leaders + grassroots voices
- No external partners or institutions were invited to this round



6 Main Results of the Needs Assessment

Key Gaps Identified

- Staff capacity is overstretched
- Inadequate training
- Limited funding
- Digital skills are low
- Leadership

Opportunities for Growth

- Communities are eager to engage
- Train local leaders
- Leverage digital tools
- Amplify advocacy voices

Strategic Areas for Future Development

- Build human resource strength
- Launch continuous training programs
- Strengthen fundraising capacity
- Invest in digital literacy
- Empower community leadership



3 Main Results: Human Rights and Addressing Discrimination

- Research indicates that 60% of individuals, 6 out of 10 people, have reported experiencing discrimination in their daily lives.
- Most common in communities, public places, and workplaces.
- People are often treated as contagious or excluded from society.
- Fear of rejection is stronger than fear of the disease itself.
- Many feel isolated, disrespected, and emotionally hurt.
- Some reported low discrimination, due to without visible disability often receive support from NGOs or local organizations.
- Primary Health Centers treat most people who are grouped (residing in leprosy colonies) equally and respectfully.
- But even university hospitals, a few were denied treatment or asked for a "cure certificate", looked at them with disgust, suggesting that they go to specialized leprosy hospitals.
- There is an urgent need for increased awareness, rights training, and the establishment of robust anti-discrimination laws, along with stronger legal protections against discrimination.



7 Key Recommendations for Capacity Building

- Build Visionary and Inclusive Leadership
- Strengthen Fundraising Skills
- Empower Youth Leaders
- Promote Responsibility and Accountability
- Support and Engage Volunteers
- Amplify Advocacy and Survivor Voices
- Build Strategic Partnerships



4 Lessons & Solutions from the Grassroots & What We Learned

- People outside the colonies know less about their rights and schemes.
- Fear of stigma stops people from seeking help or getting documents for social entitlements.
- Lack of biometric ID due to fingerprints blocks access to pensions and health benefits.
- Those with disabilities or low literacy are most excluded.
- Awareness was the most repeated need, over 80 times.
- People are asking not just for help, but for dignity and acceptance.

What Needs to Change

- Add trained counselors in leprosy programs to address mental health.
- Send mobile health teams to reach remote and isolated individuals.
- Allow alternative ways to prove identity when ID is missing.
- Run awareness campaigns using local language, drama, and radio.
- Help people reintegrate—offer jobs, schooling, and housing.
- Make dignity and social inclusion part of every service.

Our Message to the World

- The cure exists, but the stigma is still strong.
- People affected by leprosy need more than medicine—they need justice.
- Their voices are not complaints—they are a call to action.
- Start with empathy. Lead with awareness. Change must be structural.



8 Wish list for Change Before the Next ILC

1. Grassroots Leaders Are Trained, Confident, and Leading Change
2. APAL Has Sufficient and Skilled Staff Across All Regions
3. Sustainable Funding Powers Community-Led Programs
4. Digital Tools and Skills Transform Community Outreach
5. Youth Are Frontline Advocates and Innovators
6. Women Affected by Leprosy Are Empowered and Economically Independent
7. Persons Affected by Hansen's Disease Drive Advocacy Agendas
8. Volunteers Are Respected, Supported, and Engaged
9. Stigma Is Challenged Through Visibility and Media Engagement
10. Strategic Partnerships Break Down Systemic Barriers

