



SKSS

Saksham Kushthanteya Swabhimani Sanstha

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website:



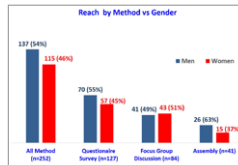
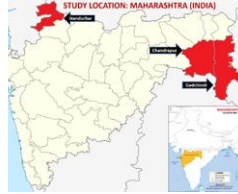
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1 Voices of Those Who Deserve Rightful Attention and Action

DATA COLLECTION METHODS

- Method 1- Questionnaire Survey:** Targeted literate individuals with informed written consent. Facilitated by SKSS members, the survey included 25 questions in two parts: Part 1 – Right to Physical & Mental Health (12 Qs), Part 2 – Human Rights & Anti-Discrimination (13 Qs).
- Method 2- Focus Group Discussions (FGDs):** Six FGDs conducted at sub-district level, organized by gender, age, and marital status. Each session was facilitated by a three-member experienced SKSS team.
- Method 3- Assembly:** Conducted with participants from diverse backgrounds (gender, age, education, marital status). Held at AWARD premises, SKSS's partner. Facilitated by the Hon. Executive Director of SKSS with team support.



REACH SUMMARY:

- Total Reached:** 252 persons affected by leprosy from rural and tribal communities (non-Colony setting) in three districts – Gadchiroli, Chandrapur, and Nandurbar (Maharashtra, India)
- Demographics:** 46% Women, 13% Children & Teenagers, 63% Adults and 24% Older Persons

2 Results- Physical And Mental Health Rights Findings

Access to Healthcare: Still Out of Reach for Many

- 1 in 10 respondents lacked access to even basic leprosy-related healthcare*.
- 26% did not receive timely medical attention treatment.
- 33% had no access to deformity care, showing serious gaps in rehabilitation.
- 1 in 4 experienced delays in receiving timely medical attention.
- Even for complications like lepra reactions, 17% were left unsupported*.

(Higher reported access may be due to respondents using LPRC services run by NGO partner, ALERT-INDIA in public health facilities, with many unable to distinguish between NGO and public health system.)

Barriers Remain High

- 31% faced obstacles in accessing essential medicines – due to cost, distance, or system failure.

Mental Health: An Overlooked Crisis

- 69% reported anxiety, depression, or isolation due to leprosy.
- Nearly half (47%) received no counselling or mental health support at all.

(Based on data gathered through Method 1 Questionnaire Survey)



3 Rights Denied: Key Findings on Human Rights & Discrimination

Discrimination Persists

- 28% faced stigma in family, community, workplace, or school.
- 1 in 5 experienced bias from healthcare providers.
- Some reported multiple layers of discrimination across settings.

Lack of Rights Awareness

- 57% unaware of their basic human rights.
- 90% unaware of anti-discrimination laws protecting them.
- 39% felt their rights were not adequately protected in the health system.

(Based on data gathered through Method 1 Questionnaire Survey)

Stigma Remains Unchallenged

- 61% believed efforts to educate society on leprosy-related stigma are insufficient.
- 56% reported collective community efforts to address rights violations.
- Just 44% engaged in any advocacy or support activity.

Neglected Economic Rehabilitation

- Only 14% received government training for economic rehabilitation.
- 82% of others urgently need economic support and capacity building.

4 From Gaps to Guarantees : Lessons & Solutions Uphold the Rights of Persons Affected by Leprosy

Persistent Gaps in Leprosy Care & Rights - Lessons for the World:

- Leprosy services remain standalone with patchy public health integration and over-reliance on NGOs.
- Misdiagnosis & poor counselling continue due to lack of trained and skilled health workers.
- Mental health & disability care for leprosy affected are neglected in Public Health System at all level.
- Stigma and discrimination persist in homes - families, communities, schools, and health facilities.
- Implementation of legal protections remains largely symbolic and ineffective, with poor awareness among affected individuals.

What Must Change – Action Priorities for Duty Bearers:

- Fully Integrate Leprosy into Public Health System at all level :**
Ulcer care, reactions, and rehab must be routine, with reliable drug & MDT supply.
- Empower Health Workforce :**
Train public and private health care providers in detection, care, referral, and counselling.
- Stigma-Free, Mental Health Support :**
Embed counselling at diagnosis; support peer groups and open dialogue to normalize leprosy.
- Rights-Based Approach :** Enforce zero discrimination, establish Grievance Redressal Mechanisms, and train officials in rights laws. Ensure accountability for neglect, non-performance, and service delivery failures.
- Economic Inclusion is Essential :**
Offer vocational training, financial aid, and equal job access—especially for women & youth.
- Build Leadership Among Affected Persons :**
Mobilize for self-advocacy, community awareness, and watchdog roles with civil society allies.

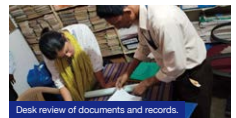
5 Organizational Needs Assessment

Methods Used:

- Meeting of Board of Executives (BoE)**
 - Special meeting held with newly appointed and outgoing BoE members, co-opted members, and the Advisor.
 - Chaired by the President and facilitated by the Advisor to ensure focused, objective-led discussion.
- Independent External Evaluation**
 - Conducted by an expert sociologist with international academic experience.
 - Included desk review (reports, SWOT, organizational documents), followed by a 2-day office visit.
 - Tools used: Individual interactions, FGDs with SKSS members and Board and On-site review of documentation, systems, and operations.
 - (This approach enabled a thorough assessment of SKSS's structure, operations, and impact.)

Participants: 19

- 9 members of the SKSS Board of Executives in addition 5 active life members of SKSS
- The Hon. Executive Director of SKSS and Advisor to SKSS and
- 2 key staff of supporting partner organisation and External Evaluator



6 Gaps & Opportunities for Development and Sustainable Growth

Key Gaps:

- No independent office or basic infrastructure; dependent on partner support.
- Members lack key skills in planning, reporting, and digital tools.
- No trained full-time staff or functional core team.
- Educational gaps limit members' technical capacity.
- Financial constraints; Limited, project based short-term funding restricts long-term growth.
- Minimal collaboration with other organisations or networks.
- No M&E system for long-term outcome tracking or strategic vision.
- Poor visibility due to weak communication and social media use.

Strategic Opportunities:

- Trusted partners & projects: Strong base for expansion.
- 10-Year Roadmap: Ready for donor confidence and policy engagement.
- Strong membership base: Potential to build local leadership and presence; Over 400 life members.
- Global stage (ILC 2025): Opportunity to share model and build alliances.
- National role: Grassroots credibility to contribute in national efforts for leprosy control & beyond.
- Broader development role: Can grow into a community development leader.

7 Capacity Building Programs Recommendations

Capacity Building Priorities for SKSS: Path to Sustainable Organisational Growth

- Strengthen Leadership & Governance:** Train members in management, planning, communication, and digital skills; enable peer learning and exposure.
- Build Human Resources:** Develop a full-time professional team with defined roles, supported by strategic advisors.
- Enhance Financial Capacity:** Create a diverse resource mobilisation plan and sustainability fund; build donor partnerships.
- Activate Membership Base:** Re-engage life members through structured outreach, team-building, and grassroots leadership development.
- Foster External Linkages:** Facilitate inter-organisational collaborations, exposure visits, and alliances to broaden perspectives.
- Institutionalise M&E Systems:** Build capacity in impact tracking and develop a long-term vision and measurable goals.
- Promote Continued Education:** Support formal education and vocational training for technically under-equipped members.
- Improve Visibility:** Enhance skills in communication via social media, storytelling, and documentation.

8 WISHLIST BEFORE NEXT ILC

System-Level Changes : Rights to Health

- Health Rights Ensured** – stigma-free access to comprehensive quality leprosy care services including mental health support.
- Grievance Redressal Mechanism established** in Public Health System and enforced.
- Accountability for gap-failures and neglect** – Public Health System become accountable for gaps and failures in performance and delivery of care-services to persons affected by leprosy.
- Zero discrimination through enforcement** of anti-leprosy stigma laws and community resolve.
- Youth-led Advocacy Forums**- State and sub-state level forums forms and become active.
- Voices of affected persons represented** in health planning, policy, and programme design.

SKSS Organisational Milestones

- SKSS Office Established** – a fully functional, independent space with core staff.
- 10-Year Roadmap in Action** – SKSS implementing, tracking, and showcasing results.
- Active Network Collaborator** – Strong presence in national forums and alliances.
- Trained & Empowered Leaders** – Members skilled in governance, advocacy, and digital tools.
- Community-Driven Programs** – Branches at grassroots delivering need-based services.
- Visible & Vocal** – Robust digital outreach and regular communication materials.
- Sustainable Funding** – Fundraising strategy active, with diverse donor and public support.