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1 Beyond the disease: the basic needs of people affected by leprosy.

Methodology

Steering Committee meeting, literature review, community forums, two discussion groups, and three online meetings.

SCOPE SUMMARY

214 people affected by leprosy were reached 150 people for forums, 30 people for the steering committee, 22 people for discussion groups and 12 people for online meetings, for a total of 214 people reached. 89 women, 26 children and adolescents (16 girls and 10 boys), 99 men.

In summary: 105 females and 109 males

5 ORGANIZATIONAL ASSESSMENT NEEDS

Methodology:

Focus groups with board members, members and residents of the village

Online meetings Participants

- Focus groups: 22 people
- Online meeting: 12 people
- Meeting with committee directeur: 12 people



2 RESULTS ON PHYSICAL AND MENTAL HEALTH RIGHTS

Access is universal:

- 1 CNAO, 8 CRAO, CHOM 70% of the regions covered
- Rural areas lack appropriate services
- The stigma of leprosy prevents many people from receiving treatment in plain sight
- Cases of loss of follow-up are numerous and complicate care



6 GAPS & OPPORTUNITY

GAPS

- No management framework documents: strategic plan, procedures manual, protection policy
- Lack of operational executives
- Lack of functional seats Weak partnerships
- No organization-specific databases

POSSIBILITIES

- Members who are too young and active
- Openness at national and international level
- Leadership in the fight against leprosy
- A good partnership with the health authorities

3 HUMAN RIGHTS AND HUMAN RIGHTS PERFORMANCE DISCRIMINATION

Discrimination has disappeared in the villages at the level of the former social reintegration villages. 90% of people who have been maimed and show signs of the disease confirm that they encounter situations of discrimination in companies and workplaces.

Report:

The data reveal a stark contrast in the fight against leprosy-related stigma. While significant progress has been observed in the former social rehabilitation villages, where discrimination seems to have almost disappeared, the situation remains worrying in the world of work. The fact that 90% of people who have been mutilated or show visible signs of the disease say they are still victims of discrimination in the workplace underlines the persistence of deep-rooted prejudices.



7 RECOMMENDATIONS FOR CAPACITY BUILDING

- Diversifying partnerships for member empowerment projects
Train members in organizational administrative and financial management
- Training in the use of digital tools and applications
- Exchange visits with better performing organizations for peer learning
- Identify and train community leaders to promote awareness and anti-stigma.

4 LESSONS & SOLUTIONS

LESSONS

- People affected by leprosy struggle to free themselves from the shackles of assistance.
- The repeal of Law 76-03 of 25 March 1976 leaves men behind:
- Support measures are needed.
- Self-stigma continues to hinder the participation of people affected by leprosy.

RECOMMENDATIONS / SOLUTION

- Develop a support programme for former social reintegration villages.
- To strengthen the self-esteem and leadership of people affected by leprosy.
- Training frontline workers on human rights and inclusion.

8 WISH LIST BEFORE THE NEXT GLOBAL FORUM

- Members access economic projects for their empowerment
- The partnership is expanding outside the leprosy sector
- Human rights training expands for members
- The development of a network between young people from different national, continental and international organizations
- Establish a participatory monitoring and evaluation system.
- Capitalize on good practices and lessons learned to adjust capacity building strategies.