

Human rights of persons affected by leprosy in the Republic of Mozambique

Submission to the 38th session of the Universal Periodic Review Working Group

Submitting Organisations

NLR Mozambique

Founded in the Netherlands in 1967, NLR International works in five priority countries, including Mozambique, to prevent, detect and treat leprosy and support health, ability and full inclusion in society for persons affected by leprosy. NLR has been active in Mozambique since 1996, providing technical support to the government's leprosy control program in three provinces.

The Leprosy Mission Mozambique (TLM)

Founded in 1974, TLM works in 20 countries towards zero leprosy transmission, zero leprosy disability and zero leprosy discrimination. In Mozambique TLM works with the government's leprosy control programme, with ALEMO to improve the livelihoods of its members through improved agriculture methods, training and advocacy, and to keep children affected by leprosy in school.

AIFO Mozambique

Founded in Italy in 1961, AIFO is involved in international cooperation projects in health and development, focusing especially on leprosy, disabilities, and diseases and conditions linked with poverty. In Mozambique, AIFO promotes the social and economic inclusion of persons disabled by leprosy, especially in regard to vocational training and access to employment.

Mozambique Association of Persons with Leprosy (ALEMO)

ALEMO is a Mozambican organisation of persons affected by leprosy, whose main area of operation is Cabo Delgado province. It works to support people affected by leprosy to become socially included and economically independent.

ADEMO

ADEMO is a Mozambican organisation of persons with disabilities, working with persons affected by leprosy in Nampula province.

ILEP

ILEP, headquartered in Geneva, Switzerland, is a federation of thirteen international NGOs working in more than 60 countries. The shared goal of its member associations is a world free from leprosy. ILEP has ECOSOC consultative status. NLR, TLM and AIFO are all members of ILEP.

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Submitted by NLR Mozambique, TLM Mozambique, AIFO Mozambique, ADEMO Monapo, ALEMO Cabo Delgado, and ILEP, October 2020

Key Words

Leprosy, social protection, non-exclusion, non-discrimination.

Introduction

1. This submission highlights the importance of equal medical and health care for all citizens, and the right to assistance of people with leprosy and in case of disability or poverty enshrined in the constitution of Mozambique¹. In practice, however, the right to medical and health care and assistance for people with leprosy, especially women, is violated by lack of a proper and consistent national health care plan and no allocation of budget to address morbidity management of leprosy-related complications. This submission makes four recommendations for government action.
2. This submission has been written in consultation with the other two ILEP partners working in Mozambique (TLM Mozambique and AIFO Mozambique) as well as local organizations working with leprosy, ADEMO Monapo (a Disabled People's Organization working on leprosy in Nampula province) and ALEMO Cabo Delgado (Mozambique Association of Persons with Leprosy)

Leprosy in Mozambique and Government commitment to elimination

3. Leprosy is an infectious neglected tropical disease (NTD), caused by a bacterium, *M. Leprae*, that mainly affects the skin, peripheral nerves, and the eyes, which can result in long-term consequences. If left untreated, leprosy can cause paralysis and disfigurement of hands and feet, such as shortening of toes and fingers, chronic ulcers on the hands or the soles of the feet, and blindness. As the disease attacks the nerves, persons affected by leprosy do not have sensation in the affected body parts, which can easily lead to disabilities. The fact that there is an increased risk for a leprosy patient's family and neighbours to become infected with the disease, makes leprosy a significant social and communal challenge.
4. In 2008, Mozambique officially declared the elimination of leprosy at national level. However, this political declaration was not followed by measures that safeguarded surveillance, full treatment of new patients, and prevention of new infections. Instead, the Mozambican government reduced the allocation of resources to the National Leprosy Control Program (NLCP), with the result that the number of new leprosy cases is rising and no consistent program to address is in place nor a specific budget to allocate the program. With no government budget allocation for the NLCP, leprosy becomes the most neglected of the neglected tropical diseases (NTDs) in Mozambique. The NLCP only has one staff member at central level, managing a disease spread in an area where more than

¹ Article 89, Constitution of Mozambique (2004): " All citizens shall have the right to medical and health care, within the terms of the law, and shall have the duty to promote and protect public health". Article 95: "1. All citizens shall have the right to assistance in the case of disability or old age. 2. The State shall promote and encourage the creation of conditions for realising this right".

45% of the Mozambican population live².

5. The NLCP is theoretically guided by the Global Leprosy Strategy 2016-2020, and the Ministry of Health declares commitment to the three pillars of the strategy, (i) Strengthen government ownership, coordination and partnership; (ii) Stop leprosy and its complications; and (iii) Stop discrimination and promote inclusion. However, questions arise as whether the Government is really addressing the key intervention areas, especially the ones to do with Ensuring political commitment and adequate resources for leprosy programmes and Strengthening surveillance and health information systems for programme monitoring and evaluation (including geographical information systems)³. Since the official declaration of eradication of leprosy in Mozambique in 2008, the Ministry of Health has not shown proactivity in designing a leprosy strategy nor a funds allocation consistent with the commitment to zero leprosy and strengthening ownership and coordination⁴.

Medical care and physical rehabilitation

6. Adequate health care is unaffordable for many people living with leprosy in Mozambique. Poor health care and late diagnosis lead to delays in treatment, and consequently onset of disabilities. Reports on misdiagnosis of leprosy were common in repeated consultations and discussions of leprosy groups with NLR Mozambique in Mossuril district⁵. The district leprosy supervisors working in each district lack proper training and equipment to screen and make a conclusive diagnosis of leprosy. There are still many remote areas, where people with leprosy live, that are not reached by district supervisors due to lack of means and being only one to cover a district of about 250 000 people or more. The NLCP lacks an induction package for newly appointed leprosy supervisors, who stay on the job for few years and move to another task right when they were starting to know the disease.
7. There is lack of collaboration between the Ministry of Health and the Ministry of Gender Children and Social Action to effectively address Pillar 3 of the Strategy on the promotion of societal inclusion by addressing all forms of discrimination and stigma, and promotion of access to social and financial support services. A survey carried out by NLR Mozambique in 2020⁶ showed that nine out of ten people with leprosy grade two disability are in need of physiotherapy in the districts of Memba and Erati and they do not have access to it; mostly due to lack of facilities in their communities and/or districts or longer distances to where facilities are available.

Discrimination and exclusion

8. As reported to NLR Mozambique by Ms Fátima Muacigarro, during a focus group discussion conducted in Monapo district in Nampula province, *“people do not understand that this disease can be cured. They still think it is a curse from God because my family did something wrong. So, people avoid me, and I fell discriminated even in groups of people with other disabilities”*⁷. Stories like this

² INE, Census 2017. <http://www.ine.gov.mz/iv-rgph-2017/mocambique/apresentacao-resultados-do-censo-2017-1>

³ WHO, The Global Leprosy Strategy 2016-2020

⁴ MISAU, Relatório de Execução Orçamental Janeiro a Março 2020. This report does not mention any expense allocated to leprosy. Discussions with the National Coordinator of the NLCP show that Government has pledged about 1 million meticals in 2019 but has not availed the funds.

⁵ NLR Mozambique Focus Group Discussions in 5 districts of Nampula province in Mozambique, 2020.

⁶ NLR Mozambique Research Report, conducted by NLR Mozambique in June 2020 in the framework of CORNTD sponsored project “Improved delivery of / access to Morbidity Management and Disability Prevention (MMDP) / Disease Management, Disability and Inclusion (DMDI) for persons affected by lymphatic filariasis, leprosy, and/or kongo in Nampula, Mozambique”.

⁷ Focus group discussion conducted in Mossuril district on 10th June 2020, facilitated by Domingos Nicala (NLR staff).

one are common when discussing with people with leprosy. The lack of government wide sensibilization campaigns makes communities continue excluding people with leprosy, especially women, from their right to participate and be counted in local income promoting activities. Government seems not aware of the UN Resolution 65/215 of 21 December 2010 on the elimination of discrimination against persons affected by leprosy and their family members. Consequences of discrimination are much more felt by women and children, leading us to infer that “leprosy has a significantly adverse impact on women, children and other vulnerable groups”⁸. Failing to protect people with leprosy against discrimination, the Government of Mozambique is contributing to the ostracization of people with leprosy even by other vulnerable groups from whom they would like to join in self-care groups.

9. Persons affected by leprosy and their family members contacted by ILEP members in the course of their work report exclusion from participating in public actions within their communities even after they finished their treatment. The potential for their development is suppressed by lack of clear and palpable measure to promote them. *“I am a good tailor, and I used to produce all the school uniforms in my community for children. But once people got to know I had leprosy; they are no longer coming to my shop. They would rather go to another tailor in the next village. I cannot make my living now”*. Amisse Juma is a cured man now, he cannot contaminate *M. Leprae* to another person, but the community has the age old mentality of leprosy being a curse. The government is not promoting the UN resolution, especially on the statement, *“Persons affected by leprosy and their family members are entitled to develop their human potential to the fullest extent, and to fully realize their dignity and self-worth”*⁹.

Recommendation 1

10. The Government should allocate a specific budget for the National Leprosy Control Program to support technical training of all the health staff involved in the programs, adequate monitoring and follow up of cases in the communities, and proper documentation.

Recommendation 2

11. The Ministry of Health should coordinate with the Ministry of Gender Children and Social Action to follow up on the poor and excluded leprosy patients and their families and ensure that adequate social protection measures are taken both for social integration and financial support.

Recommendation 3

12. The Government should adopt and enforce the implementation of the UN Principles and Guidelines on the elimination of discrimination against persons affected by leprosy and their family members. This will ensure that both health practitioners and society at large are committed to the promotion and protection of persons with leprosy and their families.

Recommendation 4

13. The Government should adopt policies for *continuum of care* in the communities, creating guidelines for community-based rehabilitation. This will not only benefit people with disability caused by leprosy, but also all those with impairments that can be corrected by physical therapy.

⁸ UN, Human Rights Council Advisory Committee, 5th Sessions, 5 August 2010.

⁹ Ibid

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