

HUMAN RIGHTS OF PERSONS AFFECTED BY LEPROSY IN SIERRA LEONE

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

Submitting Organisations

National Association of Persons Affected by Leprosy – Sierra Leone (NAPAL-SL)

NAPAL was formed in 2018 as a national body in order to advocate on behalf of its membership who might be affected directly or indirectly by leprosy, to eradicate stigma and promote social inclusion of all persons affected by leprosy, and to complement leprosy control activities through early case detection and referrals.

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German Leprosy and Tuberculosis Relief Association (GLRA)

Founded in 1957, initiate and supports leprosy and control activities in many countries through a wide range of activities including provision of assistive devices, food allowances, medical facilities, clothing, and shelter and educational support for persons affected by leprosy and their children as the case maybe. GLRA has been working in Sierra Leone since 1966.

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International Federation of Anti-Leprosy Associations (ILEP)

ILEP 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's office is in Geneva, Switzerland. ILEP has ECOSOC consultative status.

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INTRODUCTION

Leprosy is one of the oldest diseases known to humans. Exclusion from society has been a feature of leprosy from its earliest description onwards. Throughout its history leprosy has been much feared and misunderstood. Advances in medicine over the years have turned leprosy into a completely curable disease that is rendered non-infectious within a short period of starting treatment. That notwithstanding, many people are unaware of this and maintain a certain distance from people affected by leprosy, who because of late referrals have developed ulcers and visible disabilities to feet, hands or eyes, with the belief that one could be infected by getting close to them. This continuous high level of stigma and discrimination pose major obstacles in our efforts to remove the scourges of leprosy from our society.

In Sierra Leone, experience has shown that both the medical and social dimensions of leprosy must be addressed. In this submission, the medical, social and political aspects related to the impacts of stigma and discrimination on leprosy are elaborated, and recommendations are made to improve the human rights of persons affected by the disease.

THE HUMAN RIGHTS POSITION RELATED TO PEOPLE AFFECTED BY LEPROSY

NAPAL's observations over the years indicate that although there is no legal instrument discriminating and stigmatizing against persons affected by leprosy in Sierra Leone, the social perception of some people in various communities could be considered discriminating and stigmatising towards persons affected by leprosy because of the long standing cultural beliefs and practices. Most persons affected by leprosy tend to suffer from stigma and discrimination as a result of their visible disabilities even when they have been cured of the disease.

Psychosocial misconceptions of leprosy

Stigma is a mark of degradation that sets a person apart from others especially when a person is labelled by their disease; they are no longer seen as an individual but as part of a stereotyped group. It could also be a 'social devaluation of a person' or seen as an outright dehumanization of the individual. The discriminatory tendencies that result from stigma lead to disadvantages in many aspects of life, including personal relationships and work. People in society tend to be apprehensive about coming into contact with people affected by leprosy, and hesitate to relate freely with them. Victims of stigma tend to accept the discrediting prejudices held against them, which affect their self-esteem and lead to feelings of shame, a sense of alienation and social withdrawal. In anticipation of how society will react towards them, they prefer to be self-isolated.

In Sierra Leone, regardless of the language, culture and tradition, some people regard leprosy to be associated with witchcraft or some curse. This has led to social form of stigma and discrimination for people who have been cured from the leprosy disease but still have physical disabilities. These are categorized in the following headings:

Employment and Livelihood

Article 27 of the UNCRPD urges “States Parties to recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities”. However, reports in Sierra Leone have revealed that these rights are disregarded by some employers because of their negative perceptions and beliefs about the disease. Some persons affected by leprosy have been denied employment opportunities because of their disabilities due to leprosy disease.

In some cases, when people affected by leprosy developed their own businesses, they also have to face stigma in one way or another. Stigma and discrimination towards them are extended to products they sell, especially food items, thus curbing their desire to engage in some income generating activities and adding financial insecurity to the social isolation they experience.

Health and social services

Health practices in Sierra Leone encourage integration of leprosy into the general health services so that leprosy patients are treated in the same outpatient department as those with any other disease. This signals to patients and their communities that leprosy is not a 'different' disease. Such positive attitudes of health professionals can contribute significantly in the reduction of stigma due to leprosy.

However, persons affected by leprosy in our observation identified hesitation and reluctance on the part of medical practitioners to provide care when they are sent to health facilities. Some health workers who are assumed to know and understand aspects of the disease are sometimes reluctant to help people affected by leprosy, especially those with ulcers and severe disabilities, who may require health attention. This tendency reinforces stigma associated with the disease. There have also been reports that health workers refuse to visit leprosy wards in some of the hospitals. Patients are left to take care of their leprosy ulcers. Sometimes when the health workers are doing rounds in the wards they do not come close to the patients when giving them medication.

Marriage

There have been reports in the past about persons affected by leprosy being faced with stigma and discrimination in their marital life. Sometimes they are rejected by their spouses as a result of pressure from relatives. Parents or relatives of spouses put pressure on their children or relatives to break up with their spouse in order to protect their family status against stigma. This rejection sometimes stems from the vicious cycle of poverty and disability. Fortunately, such attitudes of people towards persons affected by leprosy are changing because more people now have knowledge about leprosy.

Use of public places and facilities

GLRA Sierra Leone has also noted over the years that persons affected by leprosy have been discriminated against on the basis of accessibility, as most public places are not accessible to persons with disability. A recent training on community based inclusive development, which followed an accessibility audit, highlighted that a good number of public buildings including the law court, police stations, house of parliament, ministerial buildings and even schools are not accessible to persons with disability. This poses considerable challenges for persons with disability to compete with able persons for livelihood opportunities.

Because of their untreated ulcers, Persons affected by leprosy have also been denied access to places of religious worship, public transport, restaurants, hotels, etc.

RECOMMENDATIONS

1. The Government of Sierra Leone should investigate all customary laws, beliefs and practices that discriminate against persons affected by leprosy, and address any discriminatory laws or policies and criminalize anyone who discriminates against persons affected by leprosy.
2. A multi-sectorial framework and mechanism should be developed involving relevant ministries, persons affected by leprosy, parliamentarians, non-governmental organizations, professional bodies, corporate sector and community-based organizations to address issues related to stigma and discrimination.
3. The medical training curriculum should be revised to include more leprosy training and courses for health staff to improve their knowledge and attitude towards persons affected by leprosy
4. Government should enforce a nation-wide free medical service for persons affected by leprosy with related ulcer and disabilities.
5. Government should be held accountable to implement Article 9 of the UNCRPD which focuses on accessibility: to enable persons with disabilities to live independently and participate fully in all aspects of life. It urges States Parties to take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, among others, buildings, roads, information, transportation, etc. This will help persons affected by leprosy to access public buildings, transportation etc

6. Government should be held accountable to implement Article 27 of the UNCPRD which, focuses on work and employment to promote the employability of persons with disability. It urges States Parties to recognize the right of persons with disabilities to work, on an equal basis with others. This includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, among others:

- i) Prohibit discrimination on the basis of disability with regards to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe healthy working conditions;
- ii) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions.