

REPORT ON THE SITUATION OF WOMEN AFFECTED BY LEPROSY IN INDONESIA

Submitted for the consideration of the 78TH Pre-Session of the CEDAW Committee

**Submitted by:
Organizations in Indonesia that work for Persons Affected by Leprosy
(listed below)**

(The submission may be posted on the OHCHR website)

This submission is made by a group of 14 organisations in Indonesia that actively advocate for the fulfilment of the rights of persons affected by leprosy.¹ Most of these organisations are directly led by persons affected by leprosy. In others, they play a significant participatory role in organisational decisions. ILEP, a federation of anti-leprosy agencies based in Geneva, has supported the process.

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Contributors

This report is written jointly by several organizations in Indonesia that actively advocate for the fulfilment of the rights as citizens for women, men and children affected by leprosy. The organizations are:²

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- Indonesian Disabilities and Leprosy Care Movement (GPDLI), Tangerang, Banten
- Self-Care Group (KPD) Grati, Pasuruan, East Java
- Self-Care Group (KPD) Lamongan, East Java
- Self-Care Group (KPD) Subang, West Java
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- Independent Leprosy Association (PerMaTa) East Java
- Independent Leprosy Association (PerMaTa) East Nusa Tenggara
- Independent Leprosy Association (PerMaTa) South Sulawesi
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Information and facts disclosed in this report have been discussed in meetings and consultations with those organizations, of which the participants included persons affected by leprosy.

¹ Persons with personal experience of leprosy prefer this descriptive term. The alternative term 'persons with leprosy' is rejected as being more descriptive of persons currently suffering from the disease, rather than its consequential effects in terms of disability, stigma and discrimination.

² Alphabetical order.

Context

Leprosy in Indonesia

According to WHO around 208,619 new cases of leprosy were reported from 159 countries in the year 2018³. However many millions are thought to go unreported⁴. An estimated 20-25% of persons affected by leprosy experience disability.⁵

Indonesia ranked as the third contributor to new cases in the world with more than 17,000 new cases of leprosy detected each year, including more than 6,300 women and nearly 2,000 children. These numbers have remained essentially static for the past ten years. Stigma attached to women and men affected by leprosy impedes case-finding and early treatment and increases the risk of disabilities due to leprosy. Many local terms referring to leprosy that have negative connotations, such as *contemptible disease*, *curse*, and *highly contagious*, have also contributed to the complex social problems experienced by women affected by leprosy.

Although there are more and more inclusive work initiatives between leprosy organizations, disabilities organizations and civil society organizations, stakeholders still see leprosy merely as health issue that is sufficiently discussed only in health sector forums, and not a multi-sector issue which should also be discussed in women's forums and other multi-sector engagements. Joint efforts need to be made to ensure the fulfillment of the rights of women affected by leprosy as both local and global citizens.

Principles and Guidelines on the Elimination of Discrimination Against Persons Affected by Leprosy and their Family Members

The concern shown by the UN Human Rights Council towards discrimination experienced by persons affected by leprosy and their families led to the formulation of *Principles and Guidelines for the Elimination of Discrimination Against Persons Affected by Leprosy and their Family Members* (2010) which were adopted by the UN General Assembly and the Human Rights Council. These Principles and Guidelines clearly emphasize the role that the national governments must play in eliminating discrimination against women and men affected by leprosy and their families. Global commitments to promote and protect the equality and rights of women cannot be fulfilled so long as women affected by leprosy face discrimination and their rights are not respected.

Despite adoption of the resolution on the Principles and Guidelines, women affected by leprosy continue to be discriminated against in many ways. The Principles and Guidelines complement many rights recognized by the CEDAW convention. Discriminatory practices against women affected by leprosy are in violation of the principles and obligations enshrined in Part I of the convention. In Indonesia, the Principles and Guidelines document was translated and published by the Human Rights Council of Indonesia on 2014 and piloted by PerMaTa South Sulawesi. However, apparently, after 2015 the HRC of Indonesia has shown neither any interest nor communication with organizations related to the leprosy topic.

Guidelines for Strengthening Participation of Persons Affected by Leprosy

Guidelines for Strengthening Participation of Persons Affected by Leprosy in Leprosy Services (2011) were developed in consultation and active partnership of persons affected by leprosy. The Guidelines were published by WHO to promote change from a provider-centred approach to an individual-centred one aimed at responsibility and shared decision-making. It also recognized that

³ WHO Weekly Epidemiological Record, 30 Aug 2019

⁴ 2 <http://journals.plos.org/plosntds/article?id=10.1371/journal.pntd.0003658>

⁵ ILEP technical guide. Facilitating the integration process: a guide to the integration of leprosy services within the general health system. London: ILEP; 2003. [30 March 2010]. www.ilep.org.uk/library-resources/ilep-publications/english/

the family members of person affected by leprosy play an important role in assisting the individual in their daily lives and, in addition, help in the delivery of services.⁶

In Indonesia, the *Guidelines for Strengthening Participation of Persons Affected by Leprosy* have been translated into Bahasa Indonesia and tested in the *Strengthening Participation of Persons Affected by Leprosy (SPP)* project in 4 regencies in East Java and South Sulawesi in 2011-2014. This initiative positively resulted in a number of female and male champions of persons affected by leprosy and leprosy organizations, which until now are actively carrying out community awareness and participating in development planning activities in their regions, as an effort to reduce stigma and discrimination against women, men and children affected by leprosy.

Promoting the rights of women affected by leprosy within the CEDAW framework

Stigma and discrimination against women affected by leprosy lead to many obstacles in accessing various rights guaranteed in the CEDAW convention. These are outlined in the following sections of this Report.

1. Legal and political rights and citizenship *CEDAW Articles 7, 9 and 15*

CEDAW Article 7: Participation in Political and Public Life

In the 2019 general election, many voting booths and ballots were inaccessible to women affected by leprosy who have problems with vision and touch. Nail (styluses) were too small/thin, making it difficult for women with leprosy-related impairments who have problems with damaged fingers or hands.

CEDAW Article 9: Nationality and Citizenship

A person affected by leprosy in East Nusa Tenggara has only received an electronic ID (e-KTP) in 2019 despite efforts to make e-KTP since 2016. The ID issuance was postponed because the person was deemed unable to show fingerprint records.

CEDAW Article 15: Legal capacity

Women with impairments caused by leprosy to their fingers (especially thumb) cannot become bank customers, because at the registration a fingerprint (thumb) record is required as an authentic proof of identity. As a result, women affected by leprosy have to be obliged to use the fingerprint of family members for the registration process, or even ask others to register as a customer on their behalf.

Recommendations:

- The nail (stylus) at elections should be replaced with a larger tool that can be held by persons who have problems with fingers/hands.
- The use of fingerprint records as an official way to determine authentic self-identity needs to be reviewed. A doctor's certificate explaining the condition of persons affected by leprosy might be an alternative.
- Leprosy organizations should be supported to open a complaints center (crisis centre) for cases of right violation of women affected by leprosy.

⁶ <https://www.who.int/lep/resources/B4726/en/>

2. Marriage

CEDAW Article 16

Law No. 1/1974 concerning marriage discriminates against women with disabilities, including women with leprosy related disabilities. Law No. 1/1974 Article 4 Paragraph (2) says:

*Court referred to in paragraph (1) of this article only gives permission to a husband who will have more than one wife if: a) the wife cannot carry out her obligations as a wife; b) **the wife has physical disabilities or an incurable disease**; c) the wife cannot produce offspring⁷*

Meanwhile, in the Explanation section of Article 39 Paragraph (2), reasons that can be used as a basis for divorce include:

e) One of the parties has a disability or, a disease which results in not being able to carry out obligations as a husband/wife

The confirmation of Law No. 16/2019 concerning Amendment to Law No. 1/1974 concerning marriage, has drawn criticism from many parties because the new law retains many things considered discriminatory against women and children in the previous law.

In 2017, a prospective bride was rejected by her prospective bridegroom after he discovered that she had previously had leprosy. In another case, in November 2018, a housewife with six children was divorced by her husband and evicted by her parents-in-law after they found out that the woman was detected as having leprosy. In another case, a 29 year old woman affected by leprosy in Bulukumba Regency, South Sulawesi, was ostracized by her family and community and was left by her husband. She became severely depressed due to her conditions of exclusion in a hut behind her family's house.

Recommendations:

- The Marriage Laws 1/1974 and 16/2019 need to be immediately amended based on existing laws and respect for women's rights, including women with disabilities.
- Socialization and awareness-raising about the rights of women with disabilities, including women affected by leprosy, is needed among community leaders, religious leaders, and institutions of marriage organizers.
- Community awareness programs are critically important in changing the attitudes of current and prospective husbands and parents-in-law.

3. Right to equality in education

CEDAW Article 10

A daughter of a family affected by leprosy in Banten was prohibited from going to college by her own family even though she had received a scholarship. Even though the girl does not have leprosy, her family is afraid she will be stigmatized because of her parents and because they live in a leprosy village.

In 2018, a 13-year-old child in Belu District, NTT was expelled from school because the parents were affected by leprosy. PerMaTa took advocacy initiatives to the schools and the District Education Office so that finally this child can continue in education. Similarly, a child whose

⁷ <https://kemenag.go.id/file/dokumen/UUPerkawinan.pdf>

parents have had leprosy is at risk of being expelled from school at the request of other students' parents. This case in North Sumatra is still being monitored by Indonesian Disabilities and Leprosy Care Movement (GPDLI).

Recommendations:

- Leprosy socialization activities need to be carried out more intensively in schools so that girls and boys affected by leprosy are accepted and do not experience discrimination in schools. Organisations of persons affected by leprosy should be recruited to undertake these activities.
- Civil society organisations should be encouraged and funded to make child-friendly and inclusive approaches to assist girls and boys affected by leprosy.

4. Right to equality in health

CEDAW Article 12

Every year there are just under 2,000 new cases of leprosy in children. This is estimated to include around 700 girls, but this data is not recorded or not reported. This number has remained static over the past 5 years: the exact reasons for this are not known yet because research on leprosy cases in children is minimal in Indonesia. In the national leprosy data, there is no data segregation about the number of girls with disabilities due to leprosy. Handling of leprosy cases in girls and boys is still limited to medical treatment (early detection for case finding, treatment and prevention of disability conditions). There are no non-medical interventions carried out to ensure the fulfilment of the rights of girls affected by leprosy, with and without disabilities.

In one of the general hospitals that was previously a leprosy hospital, women and men affected by leprosy cannot be treated in a public ward even if the disease is not due to the condition of leprosy. As soon as the patient is known to be a person affected by leprosy, she and her family are directed to the leprosy special unit/ward. This illustrates the prevalence of stigmatising attitudes in the health services, even in areas where leprosy is well-known.

Recommendations:

- Because of the risk of lifelong disability and discrimination, serious study should be undertaken as to why there is no decline in the number of girls and boys diagnosed with leprosy each year.
- The recording of cases of girls and boys affected by leprosy needs to be made more complete with data segregation based on gender and leprosy condition.
- Disaggregated national data needs to be collected on the condition of women affected by leprosy who have completed treatment and the number of them who have disabilities.
- Awareness and training activities about leprosy need to be done continuously to health workers, to correct wrong understandings about leprosy in the health service
- The government needs to be more vigorous in providing open, clear and accurate public awareness programs about leprosy in Indonesia in order to reduce stigma and discrimination against women affected by leprosy.

5. Right to equality in employment

CEDAW Article 11

Women affected by leprosy routinely experience discriminatory treatment in job applications and in the workplace. This treatment may result in the woman being unfairly dismissed or deciding to quit her job to avoid discriminatory behaviour.

In NTT, two women affected by leprosy were discriminated against by their fellow factory workers. The workers asked the company to terminate their jobs. However, the owner and employer in the company refused the demand and instead gave good treatment because he had received training from leprosy officers and leprosy organizations in the region.

In 2014, a woman who is a teacher in a private elementary school in North Sulawesi received discriminatory treatment and was expelled from the school by the Teacher and Parents Forum after it was learned that she had previously had leprosy.

Recommendations:

- Affirmative action and special assistance, including workplace counselling, is needed to enable equal employment opportunities by women affected by leprosy.
- There need to be regular programs of socialization and awareness-raising about gender and leprosy among companies and other employers.