

# REPORT ON THE SITUATION OF PERSONS AFFECTED BY LEPROSY IN INDONESIA

Submitted for the consideration of the 13<sup>th</sup> Pre-Session of the CRPD Committee

Submitted by:  
**Organizations in Indonesia that work for Persons Affected by Leprosy  
(listed in Section 1 below)**

(The submission may be posted on the OHCHR website)

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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.<sup>1</sup> 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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## 1. Contributors

This report is written jointly by several organizations in Indonesia that actively advocate for the fulfilment of the rights as citizens for Persons Affected by leprosy, as guaranteed in the CRPD. The organizations are:<sup>2</sup>

- Hansen Indonesia Reintegration Federation (FARHAN), Tangerang, Banten
- Cirebon Disabilities Communication Forum (FKDC), Cirebon, West Java
- 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
- Self-Care Group (KPD) Tegal, Central Java
- Leprosy Care Community, Depok, West Java
- Mimi Institute, Jakarta
- NLR Indonesia, Jakarta
- Independent Leprosy Association (PerMaTa) East Java
- Independent Leprosy Association (PerMaTa) East Nusa Tenggara
- Independent Leprosy Association (PerMaTa) South Sulawesi
- Tomotouw, Manado, Sulawesi Utara

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.

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<sup>1</sup> 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.

<sup>2</sup> Alphabetical order.

## 2. Background

According to WHO around 208,619 new cases of leprosy were reported from 159 countries in the year 2018<sup>3</sup>. However many millions are thought to go unreported<sup>4</sup>. An estimated 20-25% of persons affected by leprosy experience disability.<sup>5</sup> Evidence-based studies indicate that children constitute 10 percent of the new cases diagnosed. This means that every 30 minutes, one child is diagnosed with leprosy.

Indonesia ranked as the third contributor to new cases in the world with more than 17,000 new cases of leprosy detected each year, with the percentage of 10-11% of cases in children tending to stagnate over the past 5 years. The stigma attached to the patients or persons affected by leprosy constrained the case finding and early treatment in an effort to prevent the occurrence 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 persons affected by leprosy.

Although there are currently 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 multi-sector forums. Moreover, disabilities stakeholders often do not even involve persons with disabilities due to leprosy into their policies and programs. These conditions have resulted in persons affected by leprosy being more excluded from various development sectors.

Addressing the above conditions, global joint efforts need to be made to ensure the fulfillment of the rights of persons affected by leprosy as both local and global citizens. This report is expected to be taken into consideration by decision makers at the international levels, UN Committees and agencies, as to be described in more detail in the next section.

## 3. Reporting mechanism to the UN Committee (Human Rights Council, CRPD Committee) regarding the situation related to the rights of person affected by leprosy, is to be delivered through:

- *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 of 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 persons affected by leprosy and their families. It makes us realize that global commitment to promote and protect human rights of individuals cannot be fulfilled so long as persons with leprosy related disabilities face discrimination and their rights are not respected.

Despite adoption of the resolution on the Principles and Guidelines by the Human Rights Council and its endorsement by the UN General Assembly, persons with leprosy related disabilities continue to be discriminated against in many ways. The Principles and Guidelines complement many rights recognized by the CRPD. Discriminatory practices against persons with leprosy related disabilities are in violation of the principles and obligations as enshrined in article 3 and 4 of the CRPD.

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<sup>3</sup> WHO Weekly Epidemiological Record, 30 Aug 2019

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

<sup>5</sup> 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/](http://www.ilep.org.uk/library-resources/ilep-publications/english/)

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. The pilot successfully developed the enterprise self-care group as an entry point model to involves persons affected by leprosy and their family members in the community. Apparently, after 2015, the HRC of Indonesia has shown neither any interest nor communication with organizations related to the leprosy topic.

- *UN CRPD Shadow Report, List of Issues, Pre & Session of Constructive Dialogue*  
Representatives of leprosy organizations in Indonesia actively contributed in the discussion and preparation of the UN CRPD Shadow Report of 2012. Likewise in 2019, they also participated in the drafting of this submission to the *List of Issues*.

#### **4. Guidelines for Strengthening Participation of Persons Affected by Leprosy**

Guidelines for Strengthening Participation of Persons Affected by Leprosy in Leprosy Services were developed in consultation and active partnership of persons affected by leprosy. The Guidelines were published by WHO (2011) to promote change from a provider-centred approach to an individual-centred one aimed at responsibility and shared decision-making. It also recognized that the family members of person affected by leprosy also play an important role in assisting the individual in their daily lives and, in addition, help in the delivery of services.<sup>6</sup>

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 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 persons affected by leprosy.

#### **5. Law No. 8 of 2016 concerning Persons with Disabilities**

The government of Indonesia issued Law No. 8/2016 concerning Persons with Disabilities. The order of content and composition of this law is based on the CRPD which was ratified in 2011. The law automatically replaced the previous applicable regulation: the Law No. 4/1997 concerning Disabled Persons.

Leprosy is specifically mentioned in Law No. 8/2016 Explanation Section, Chapter II Article by Article, Article IV Paragraph (1) Letter a:

*What is meant by "Persons with Physical Disabilities" is the disruption of motion function, including amputation, paralysis or stiffness, paraplegic, cerebral palsy (CP), due to stroke, due to leprosy, and small person.*

The mention of leprosy in the Law becomes a very important starting point for mainstreaming the leprosy topic in the disabilities issue in Indonesia. With the mention, persons with disabilities due to leprosy have the same rights as persons with other disabilities.

#### **6. Regulation of the Minister of Health No. 11 of 2019 concerning Leprosy Control**

The Government of Republic of Indonesia through the Minister of Health issued Permenkes No.11/2019 concerning Leprosy Control. This regulation is based on the consideration that: a) leprosy is still a health problem in Indonesia because it causes very complex problems, not only in

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

terms of medical, but extends to social, economic, and cultural problems since there is still a stigma in the community against leprosy and disabilities that are caused by leprosy; and b) that in order to implement the provision of Article 44 Permenkes No. 82/2014 concerning the Control of Communicable Diseases, it is necessary to develop guidelines for leprosy control.<sup>7</sup>

The contents of this regulation refer to the *Guidelines for the Diagnosis, Treatment and Prevention of Leprosy* published by the WHO in 2018.

7. **Promoting the rights of persons with leprosy related disabilities within the CRPD framework**  
Stigma and discrimination against persons with leprosy related disabilities lead to many obstacles in accessing various rights guaranteed in the CRPD. These are outlined in the following sections of this Report.

8. **Law, Politics and Citizenship**

- ***CRPD Article 29: Participation in Political and Public Life (Paragraph 1)***

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

- ***CRPD Article 29: Participation in Political and Public Life (Paragraph 2)***

Leprosy officers in Lamongan, East Java ask for minutes of the monthly meetings of KPD Brondong – Lamongan every year, however there has been no feedback nor follow-up from related parties. If there is something planned or decided based on the results of meetings, whose most members are persons affected by leprosy, then they should be involved.

- ***CRPD Article 18: Freedom of Movement 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. He had always failed, and the ID issuance was postponed because he was deemed unable to show fingerprint records. Persons affected by leprosy who suffer impaired finger (especially thumb) cannot become bank customers either, because at the registration a fingerprint (thumb) record is required as an authentic proof of identity. As a result, persons affected by leprosy have to be willing to use the fingerprint of family members for the registration process, or even ask others to register as a customer on their behalf.

**Recommendation:**

- The nail (stylus) 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 a 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 can open a complaints center (crisis centre) for cases of right violation of persons affected by leprosy.

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<sup>7</sup> [http://hukor.kemkes.go.id/iploads/produk\\_hukum/PMK\\_No\\_11\\_Th\\_2019\\_ttg\\_Penanggulangan\\_Kusta.pdf](http://hukor.kemkes.go.id/iploads/produk_hukum/PMK_No_11_Th_2019_ttg_Penanggulangan_Kusta.pdf)

## 9. Women

- **CRPD Article 6: Women with Disabilities**

Law No. 1 /1974 concerning Marriage still 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 offspring<sup>8</sup>*

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

*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 there are still many things considered discriminatory against women and children in the previous Law, nor were they revised and rearranged in this latest Law No.16/2019.

- **CRPD Article 16: Freedom from Exploitation, Violence, and Abuse**

In 2017, a prospective bride experienced a rejection from the prospective bridegroom after he discovered that the woman had ever had leprosy. In another case, 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 November 2018.

**Recommendation:**

- The Marriage Law needs to be immediately revised based on existing laws and respect for women's rights, including women with disabilities.
- Socialization and awareness about disabilities and leprosy needs to be done to community leaders, religious leaders, and institutions of marriage organizers.
- Leprosy organizations and persons affected by leprosy need to increase knowledge about gender in order to be able to strengthen fellow persons affected by leprosy (especially women) and advocate for the rights of women affected by leprosy.
- Peer support needs to be done by and for persons affected by leprosy.

## 10. Children **CRPD Article 7: Children with Disabilities**

- In Bulukumba Regency, South Sulawesi, a child who has leprosy has stopped attending school because he could not afford it. PerMaTa worked on this case in collaboration with PPD Bulukumba and enrolled the child to receive Education Social Assistance for Persons with Disabilities (ASPD).
- Every year there are 10-11% new cases of leprosy in children. This percentage has stagnated over the past 5 years. The exact cause is 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 children with disabilities due to leprosy.

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<sup>8</sup> <https://kemenag.go.id/file/dokumen/UUPerkawinan.pdf>

- Handling of leprosy cases in children 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 children affected by leprosy, with / without disabilities.

**Recommendation:**

- Given the stagnant percentage of cases of children, the handling needs to be more serious and get the attention of various parties including child stakeholders.
- It is necessary to conduct socialization activities about leprosy in schools so that children affected by leprosy are still accepted and do not experience discrimination in schools.
- Socialization and networking need to be done with child support organizations/ institutions.
- The recording of cases of children affected by leprosy needs to be made more complete with data segregation based on gender and leprosy condition (with/ without disabilities).
- It is necessary to make *child-friendly and inclusive* approaches to assist children affected by leprosy (with/without disabilities). In East Nusa Tenggara, two organizations working for children with disabilities also assist children affected by leprosy. The child-friendly playroom is open to all children who visit or stay temporarily in the organizations. Counselling activities about leprosy and disability are carried out to community leaders and the church.

**11. Socio-cultural CRPD Article 30: Participation in Cultural Life, Recreation, Leisure and Sports**

- A child (teenager) from a person affected by leprosy in Nganget, East Java, was refused to join the local youth group. As a result of this rejection, they took the initiative to form their own youth community. Although this initiative seems good, but in fact this action reinforces the fact of discrimination and exclusion in society.

**Recommendation:**

- Socialization and education to build awareness about equality of human rights, including persons affected by leprosy, and stigma reduction need to be carried out continuously against community leaders, religion and key groups in the community.
- Several leprosy groups in East Java, West Java, South Sulawesi and East Nusa Tenggara undertook inclusive initiatives with the disability communities to ensure that the rights of persons affected by leprosy are also discussed in disabilities mainstreaming.

**12. Stigma and Discrimination CRPD Article 8: Raising Awareness; CRPD Article 21: Freedom of Expression and Opinion, and Access to Information**

The lack of information dissemination about leprosy has resulted in stigma and discrimination against Persons Affected by Leprosy, occurring in various regions in Indonesia.

- A person affected by leprosy in Cirebon, West Java received a recommendation from the Governor of West Java to work in the PLKB (Family Planning Field Officer), but the discriminatory treatment by the person in charge resulted in this person affected by leprosy deciding to quit his/her job.
- A woman affected by leprosy in Bulukumba Regency, South Sulawesi, of age 29 years old, was ostracized by her family and community and was left by her husband. She was

severely depressed due to her conditions of exclusion in a hut behind her family's house. PerMaTa was able to assist and provide counselling to the relevant person. In early 2019 it was reported that she had died.

- 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 learning that the teacher had leprosy. This occurred in 2014.
- Discriminative treatment and stigma often come from the immediate environment of Persons Affected by Leprosy. A person affected by leprosy in Gowa, South Sulawesi was discriminated against and ostracized by his own family. He did not have access to activities outside the home like other family members. PerMaTa as a leprosy organization took the initiative to provide assistance and build awareness in the family, after which the family gradually accepted the condition of the person and acknowledged the ability of persons affected by leprosy.

**Recommendation:**

- Leprosy village (formerly called 'leprosy colony') needs to be converted as an educational place like an education museum to provide correct knowledge for persons affected by leprosy and anyone visiting the place.
- Persons affected by leprosy need to be more engaged at all levels and aspects of development. *Nothing about us without us.*
- Organizations working on leprosy topics need to organize programs and capacity building activities to encourage persons affected by leprosy to become pioneers and role models so that they become stronger in voicing the rights of persons affected by leprosy.
- Peer counselling activities need to be more available to persons affected by leprosy.
- The media needs to be involved in the more massive publication of works produced by persons affected by leprosy.
- Socialization needs to be done to health workers, because many of them still do not understand about leprosy.
- The government needs to be more vigorous in promoting openly, clearly and correctly about the status of leprosy in Indonesia; not only in early detection, but also in reducing stigma and discrimination against persons affected by leprosy.
- Several groups of persons affected by leprosy proposed the existence of a Law concerning the Fulfilment of the Rights of Persons Affected by Leprosy.

**13. Health CRPD Article 25: Health**

- In one of the general hospitals that was previously a leprosy hospital, persons 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, he/she is directed to the leprosy special unit/ward. Likewise, the person's family is also directed to the leprosy ward.
- In various regions in Indonesia, leprosy drugs (MDT) are often not available or arrive late. Especially in areas that are low-endemic or that have been declared 'leprosy-eliminated' (for example: Malang, Jambi, Palembang), drugs are difficult to obtain; patients and health centre (Puskesmas) need to wait for an uncertain time until the drug is received. In September 2019, a leprosy patient in South Sulawesi reported that his father had been deceived by a person who sold leprosy medication for Rp. 15 million (€1,000).
- In NTT, two siblings, 13 and 9 years old, were detected as having leprosy in December 2018 and had dropped out of medication in May 2019 due to late delivery of the drug. They only started treatment again in September 2019 and during the period were not

monitored by the officers nor provided explanations about self-care. As a result, the younger brother experienced Grade-2 disability (severe visible impairments).

- The leprosy elimination program only covers health aspects. Monitoring of patients is only carried out during the treatment period. In many areas, patients who have completed their medication and been released from treatment escape from the monitoring of officers, except at a later date if they experience a leprosy reaction so that they need to get treatment.
- The issue of leprosy does not receive the attention of local governments whose regions have been declared 'eliminated' or 'low endemic'.

**Recommendation:**

- The Government needs to coordinate across sectors in problems faced by persons affected by leprosy (health, education, employment, social-culture, etc.)
- Contact examination needs to be done routinely in places far from health access.
- It is recommended that leprosy officers who are usually only one person in each Puskesmas should not get the burden of carrying out other programs. Workload of staff needs to consider the quality of health services provided.
- There needs to be a solution related to the distance between the Puskesmas providing MDT drugs and the patients. The Puskesmas Pembantu (Pustu) can function as a provider of leprosy services and treatment.
- Raising awareness and training activities about leprosy need to be done continuously to health workers.
- Persons affected by leprosy and leprosy organizations should be involved in leprosy case finding and education carried out by health workers, and in the monitoring and evaluation of leprosy programs at the regional and national levels.
- The naming of 'elimination' of leprosy needs to be reviewed. In Indonesia this term is used to mean not 'elimination' (no more disease) but 'elimination as a public health problem' (one new case per 10,000 population). Areas that has been declared successful in eliminating leprosy and low endemic seem to have completed its task in handling leprosy. As the matter of fact, new cases still exist, not zero cases. Because it is considered that the number of cases is small, so the regional budget for leprosy programs is minimal and not a priority. This would become a time bomb for the region, and it is not impossible that one day the area will become high endemic again.

**14. Education *CRPD Article 24: Education*)**

- A daughter of a family affected by leprosy in Banten is prohibited from going to college by her own family even though she has received a scholarship. Even though the girl does not have leprosy, her family is afraid she will get stigmatized because of her parents and because they live in a leprosy village.
- A child whose parents have had leprosy is at risk of being expelled from school at the request of other students' parents. The case in North Sumatra is still being monitored by GPDLI.
- A person affected by leprosy in Gowa Regency, South Sulawesi was promised by the District Education Office in 2018 to take part in the Kejar Paket B and C Programs, but until 2019 it had not been realized.
- In 2018, a 13-year-old child was expelled from school because his parents were affected by leprosy in Belu District, NTT. PerMaTa took advocacy initiatives to the schools and the District Education Office so that finally this child can continue his education.



**Recommendation:**

- The Government needs to coordinate across sectors in problems faced by persons affected by leprosy (health, education, employment, social-culture, etc.)
- Leprosy socialization activities need to be carried out more intensively in schools and related agencies, involving persons affected by leprosy. Tomotou, PerMaTa and many leprosy organizations in Indonesia carry out this initiative.
- The topic of leprosy needs to be included in the curricula of health colleges and become one of the special study program choices in health schools.
- Persons affected by leprosy need to be recruited as counsellor in each Puskesmas
- Counselling also needs to be done for families of persons affected by leprosy.

**15. Occupation *CRPD Article 27: Occupation***

- In Tegal, Central Java, a person affected by leprosy was dismissed from his job because of illness and was considered to be working less than optimal.
- In NTT, two women affected by leprosy were discriminated against by their fellow factory workers. The workers asked the company to cut their job. 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.

**Recommendation:**

- It requires special assistance and counselling for persons affected by leprosy (especially those with disabilities) in the world of work to ensure their safety, comfort and presence in the formal sector.
- In the case of obtaining access to employment, there should be affirmative action to the marginalized groups including persons affected by leprosy. In Cirebon, West Java, a person affected by leprosy was accepted as a teacher at a special school (SLB). In Subang, West Java, the Government provides job opportunities for persons affected by leprosy in managing city parks. In Banten, a person affected by leprosy who works as a sweeper has been appointed as a civil servant.
- Socialization and raising awareness about leprosy and disabilities need to be done continuously to companies and agencies.
- Efforts to improve the welfare of persons affected by leprosy need to be done inclusively. The initiative of KPD Lamongan, East Java of creating a savings and loan cooperative that was originally devoted to members affected by leprosy, is now developing and providing savings and loan access to wider public. This also reduces the stigma about persons affected by leprosy in the region which were previously considered unproductive and poor.

**16. Data *CRPD Article 31: Statistic and Data Collection***

- Recognition of persons affected by leprosy during population census/data collection is very important so that persons affected by leprosy are no longer stigmatized. Persons affected by leprosy must be more confident to admit that they have leprosy and need the same access as other citizens. Without them mentioning that they have had leprosy, national data and surveys about the conditions and needs of individual person affected by leprosy will not be covered in an integrated data collection system by the Government.
- There has not been any disaggregated national data on the condition of persons affected by leprosy who have completed treatment and the number of them who have disabilities.

- Specific data about leprosy is only collected by the Ministry of Health and the Health Offices. There is no data on persons affected by leprosy in other technical ministries (for example: Ministry of Social Affairs, Ministry of Manpower)

**Recommendation:**

- It is necessary to conduct disaggregated national data collection on the condition of persons affected by leprosy after the treatment is complete. This is needed as a basis for cross-sectoral institutions/agencies to contribute to the empowerment and strengthening in development sectors.
- As it already began by the organizations of persons with disabilities, in terms of data collection in the field, persons affected by leprosy and leprosy organizations can be involved as data collection team.
- Data information about leprosy at national and local levels needs to be opened and easily accessed by the public, both online and offline.