

ISSUES TO BE ADDRESSED

- The negative social perception surrounding leprosy, also known as stigma, deeply impacts the everyday lives of individuals affected by this disease. Its effects can be seen across multiple areas, including education, marriage, employment, social relationships and accessibility to healthcare.
- Stigmas can be extremely detrimental as they can lead to the violation of several fundamental human rights such as education, work opportunities, and equal participation in society. Unfortunately, individuals suffering from leprosy often find themselves at the receiving end of such stigmatization.
- Due to their lack of resources and power, they are unable to provide evidence of human rights violations that they may be subjected to. This situation presents a major challenge for them when it comes to protesting against the wrongdoings they have experienced.
- In many cases, attempts made by individuals affected by leprosy to report such violations are dismissed as baseless. This is primarily because of the lack of education and prior segregation from society that they have undergone. It is indeed unfortunate that such individuals are often deprived of basic human rights due to the social stigma attached to their condition.
- It is crucial that we address these issues with utmost urgency and sensitivity, and work towards abolishing these stigmas and ensuring that all individuals, regardless of their medical condition, are treated with dignity and respect.



For the above reasons, PerMaTa and its partner Yayasan Dedikasi Tjipta Indonesia (YDTI) conducted a study on how people affected by leprosy can investigate and prove human rights violations against their peers.

MEASURES TAKEN

- The district of Jeneponto, located in South Sulawesi, Indonesia, is known for being both poverty-stricken and highly endemic in terms of leprosy.
- Given this context, the study team comprising six young individuals affected by leprosy from PerMaTa South Sulawesi conducted extensive preparations before embarking on their research.

Preparations:

- Participatory planning sessions were organized to ensure that all team members were on the same page and fully committed to the study's objectives. Moreover, the team informed the local health authority about the research and sought their support to mitigate any potential challenges.
- To ensure that the team was well-equipped to handle the sensitive topic of leprosy and its associated stigmas, the team conducted trainings on human rights violations and interviewing skills. The study team was prepared to collect information on stigmas associated with leprosy and any potential human rights violations that may have occurred.
- Through their thorough preparations, the study team was able to conduct their research in a professional and ethical manner. Their efforts shed light on the challenges faced by individuals affected by leprosy and the need for greater awareness and empathy towards their struggles.



MEASURES TAKEN (CONT.)

- During the preliminary investigation, we found that the local Leprosy Program proposed 31 individuals who were suspected to be affected by leprosy. Unfortunately, these individuals were already very marginalized even before being diagnosed with the disease. This further highlights the social stigma attached to leprosy which has been prevalent for a long time.
- After conducting thorough interviews, our team discovered that 8 of the 31 individuals were indeed facing possible human rights violations. These violations ranged from discrimination, prejudice to outright abuse. It was disheartening to see that even in the present day and age, people diagnosed with leprosy are still subjected to inhumane treatment and exclusion.
- To address these violations, we made the decision to select 5 individuals for further in-depth investigations. Our team went to the field to conduct interviews with the affected people, their families, neighbors, as well as other stakeholders such as the local government, health workers and educators.
- During our investigation, we used the EMIC stigma scale to estimate the level of stigma present in the communities. The scale served as both background information and evidence to showcase how deeply ingrained the stigmas surrounding leprosy are in society.



RESULTS/ACCOMPLISHMENTS

The cases mentioned, highlight the prevalent stigmas surrounding leprosy, which have led to severe human rights violations.

We have extensively documented the selected cases:

Case 1 = In the first case, the 15-year-old boy was unfairly expelled from school simply because he received treatment for leprosy and suffered from paralysis in his hands. This is a clear violation of the right to education, which should be accessible to all individuals irrespective of their health conditions.

Case 2 = Similarly, the 60-year-old man mentioned in the second case was grossly neglected by both his family and the local government. He was undernourished and forced to sleep outside his own house, which is a violation of the right to an adequate standard of living. Such neglect is often due to the stigmas related to leprosy, which is a highly treatable disease.

Case 3 = The third case highlights the issue of equal rights during marriage and its dissolution. The 21-year-old man was abandoned by his wife and her family simply because he was affected by leprosy. This is a clear violation of his basic human rights and dignity. Leprosy should not be a factor in determining one's worth as a human being or a partner.

Case 4 = The fourth case highlights how stigmas surrounding leprosy can lead to community-level discrimination. The 40-year-old woman was denied access to the road leading to her house, which is a violation of her right to freedom of movement. Such discriminatory actions by her neighbors were solely based on their prejudices related to leprosy.

Case 5 = The 60-year-old woman in question has been forbidden from using the communal well located right in front of her house by her neighbors. This blatant act of discrimination violates her right to social security and to non-discrimination, and serves as a stark reminder of the far-reaching impact of pervasive stigmas. It is crucial that society works towards eradicating such stigmas to ensure that everyone is treated with dignity and respect, regardless of their health status.



RESULTS/ACCOMPLISHMENTS (CONT.)

- During our investigation into human rights violations related to leprosy, we found that the violations were not of extreme nature, but were rather a result of ignorance and stigma within the communities, along with neglect by local authorities. The stigmas attached to this disease are still prevalent in many parts of the world, leading to inadequate education and awareness about it, even among teachers and health staff. As a result, many individuals affected by leprosy are denied their basic human rights.
- The PerMaTa Youth team was able to gain valuable experiences and skills in investigating such violations through this study. The team was able to engage with local authorities and work towards securing the rights of those affected by leprosy. By bringing attention to the issue and spreading awareness, the team was able to combat the stigma and ignorance that often lead to human rights violations.
- Despite the fact that the violations were not extreme, they were still a serious infringement upon the rights of those affected by leprosy. Through the efforts of the PerMaTa Youth team, individuals were empowered and their voices were heard. The team's work serves as an example of how dedication and perseverance can bring about positive change even in the face of deep-rooted stigmas and prejudices.



For example, the team members have been actively addressing the issue of stigmas associated with leprosy in the village. As part of their efforts, they reported about the condition of an old man who was suffering from leprosy to the health center and to the local government. Their intervention not only helped the old man get the much-needed medical assistance but also prevented any potential human rights violations that he could have faced due to the stigma associated with leprosy. The youth team's diligent efforts in addressing the issue of stigmatization have been commendable and have helped in improving the lives of those affected by leprosy in the village.

SAMPLE CASE TO SHOWCASE

Stigmas attached to certain conditions like leprosy can lead to gross human rights violations, as we discovered in a recent case.

Example:

A young boy suffering from leprosy was expelled from school as his treatment made him drowsy and left him with paralyzed hands, hence he could not properly engage in the class. Despite his parents' pleas and requests to the school authorities to provide some form of accommodation, the boy was not allowed to attend classes. This was a clear violation of his basic right to education.

We reported this matter to the Department of Education, but unfortunately, we found that proving such violations can be quite challenging, especially in cases where the victim is already marginalized due to their condition. In this case, the young boy was still registered at the school so it was difficult to prove that the boy was not allowed to enter the school. The officials were hesitant to take any action since the school had technically not barred the boy from attending, merely making it impossible for him to do so.

Despite the prevalence of stigmas surrounding leprosy, it is our duty to address the human rights violations that are often associated with this disease. In the specific case mentioned, reporting the incident to both the authorities and the school's head, allowed for increased attention to be brought to this issue. Additionally, the health center staff's visit to the school to educate students and staff on leprosy was a crucial step towards fighting against the stigmas and misconceptions surrounding this disease. Moving forward, it is important to continue these efforts and work towards creating a more accepting and inclusive society that values the health and well-being of all individuals, regardless of their medical conditions.



**The boy is now
back at school!**

LESSONS LEARNT

- People who have experienced leprosy are well-equipped to collect evidence and investigate events in detail, as they have a deep knowledge of the physical, emotional, and social impacts of the disease.
- By utilising the expertise of these individuals, we can gain a deeper understanding of the complex issues surrounding leprosy and work towards ending the stigmas and injustices associated with it.
- It is imperative that we prioritise the involvement of those who have experienced leprosy in investigating human rights violations, in order to ensure that their voices are heard and their experiences are valued.



- Individuals affected by leprosy may have limited legal knowledge to take cases related to human rights violations to court. However, it is important to note that they can still investigate violations where they happen and directly report them to the local government.
- This is especially crucial given that a majority of violations take place at the local level. Seeking professional support to file legal cases may not always be feasible, but reporting violations to local authorities can still have a significant impact in raising awareness and holding accountable those responsible.

NEXT STEPS

- Sharing experiences and lessons learned with PerMaTa branches and other leprosy organizations.
- Encouraging the government to better inform communities about leprosy to avoid human rights violations in the future.
- Providing more support to persons affected by leprosy who are experiencing human rights violations by investigating their cases.
- Raising awareness nationally and internationally that human rights violations are still occurring, often caused by ignorance and stigma.

