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Persons affected by Hansen's disease and their family members, Colleagues and partners,

This is **the final number of my newsletter as Special Rapporteur** on the elimination of discrimination against persons affected by leprosy / Hansen's disease and their family members.

My **everlasting gratitude** goes to the **organizations of persons affected by Hansen's disease**. The grassroots and national organizations of persons affected by Hansen's disease **always put themselves at the frontline, no matter what risks they take**. They have also always been ready to support, and even defend, me, if needed.

There are so many leaders of the global community of persons affected by leprosy / Hansen's disease and their family members to which I am forever grateful. Over these years, **my admiration for their resilience and determination to survive Hansen's disease and its consequences**, together with their dedication to support their peers and improve their living conditions, has only increased. **I leave office inspired by their formidable example.**

I would also like to thank **the outstanding support from amazing partners**, in particular to the **WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa and the Executive Director of Sasakawa Health Foundation and Sasakawa Leprosy Initiative Takahiro Nanri**, who through Sasakawa Health Foundation provided **key material support to my work**. I am also extremely grateful to **ILEP members** – among which I would like to highlight the **consistent cooperation from The Leprosy Mission** – and the **ILEP's secretariat**.

Given the limits of this text, I cannot thank the multitude of people who provided valuable support to my work as Special Rapporteur, whether in the form of a precious word of encouragement or of key inputs. **Many people helped me to make this mandate alive and meaningful. This was, from the start, a collective endeavor, where passion, courage and solidarity were the lights that showed us the way forward.**

You will find in this newsletter information about the activities I undertook during the previous months. You will also **find information about some of my forthcoming activities**, at a time when I am nearing the end of my term as Special Rapporteur.

I would like to dedicate this newsletter to a boy who I had the privilege to meet in Bangladesh.

I would like **to dedicate this newsletter to a boy who I had the privilege to meet in Bangladesh.** This boy, around 13 years old, dropped out of school due to discrimination. He has impairments in both hands and feet. And he also has the most beautiful smile! We cannot slow down our efforts. On the contrary, we need to work harder to make sure we fulfill this boy's rightful expectations and dreams.

As I left, **I told him that one day I would go back and that on that day I would want to hear from him that he had fiercely fought for himself and that he had never given up hope.** But unfortunately, that is too easy to say. It's much more difficult to ensure that he, and other boys and girls like him, have access to opportunities on an equal basis with others and enjoy a life with dignity. But however difficult it may be, that is our mission and duty.

In order to succeed, **I am more convinced than ever that we need to strengthen the grassroots and national organizations of persons affected** by Hansen's disease. It is there, at the national and subnational levels, that the battle can truly be won. Furthermore, we should all strengthen relations and synergies within our own community, leaving no room for internal conflicts. We should practice understanding and care within our community - which includes individuals with the personal experience of Hansen's disease and others who want to join them in their struggle for dignity and fundamental rights and freedoms - in order to grow stronger and becoming more effective. Our main enemy is neglect, oblivion and invisibility. And that is why our voice should be coherent, united and proud.

Let me close this introduction by simply saying "seeing you soon", from another position or from no position at all, but always by your side.



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Good reading!

My last official visit: to Bangladesh

In February, I carried out an official visit to **Bangladesh**. From 7th to 15th February, I met government representatives, the Law Commission, the National Legal Services Organization, the National Human Rights Commission and the National Foundation for the Development of Disabled Persons. I also met United Nations resident coordinator and agencies working in the country. Furthermore, I dialogued with a large number of stakeholders, including civil society organizations, healthcare workers and persons affected by Hansen's disease living in different districts.

I left Bangladesh genuinely impressed by **the outstanding work done by the organizations of persons affected by Hansen's disease** to advocate for their rights. I deeply thank persons affected by Hansen's disease for sharing their experiences, which they did with such a profound sense of dignity, pride and expertise.

I left Bangladesh genuinely impressed by the outstanding work done by the organizations.



Bangladesh is one of the 23 World Health Organization's (WHO) global priority countries for Hansen's disease. Having been in the country, **I can affirm that neither Hansen's disease nor discrimination on its ground have disappeared.** Both the disease and discrimination are just hidden among multiple layers of poverty, gender, disability, social class, and other grounds for discrimination. I realized that Hansen's disease is still the cause of great suffering among people who live in Bangladesh.

No frameworks for protecting rights nor providing accountability and remedies for rights violations seem to be guaranteed to persons affected by Hansen's disease and their family members in the country.

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In 2015, Bangladesh was moved out from the World Bank list of Low-Income Country (LIC) to Lower Middle-Income Country (LMIC), meeting in 2018 all the UN criteria to graduate from the list of Least Developed Country (LDC) to a Developing Country. **The government expects to formally graduate from Least Developed Country in 2024 (Bangladesh 8th Five-Year Plan).**

Bangladesh has made consistent progress regarding economic growth and considerable, even if not yet sufficient, improvement on what concerns WASH (water, sanitation, and hygiene), which comprises social determinants of diseases such as Hansen's disease and other neglected diseases that are endemic to the country.

Nevertheless, the situation of persons affected by Hansen's disease and their family members in Bangladesh shows that **the outstanding economic growth (compromised by the COVID-19 pandemic) is not reaching the entire population and casts doubts on whether fundamental principles of the right to development, such as equity, self-determination, participation, and justice are being met.**

During my official visit, I **identified good practices for eliminating discrimination** on the grounds of Hansen's disease that are being **implemented by grassroots organizations**. They bring together **not only persons affected by Hansen's disease but also persons with disabilities and members of other disadvantaged groups**. Their **practices are based on solidarity** and encompass economic empowerment, advocacy, self-care and rehabilitation.

Such good **practices for eliminating discrimination** on the grounds of Hansen's disease **should be scaled up by the government** as part of a development strategy that places people's autonomy and active citizenship at its center.

I will present **my report about Bangladesh to the Human Rights Council this June**.

[🔗 Read my press release on the official visit](#)

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Still on the topic...

The Guardian newspaper published a report about the high number of Hansen's disease cases among tea pickers in Bangladesh.

I am worried that there might be considerable underreporting of new cases in the country.



The screenshot shows the top of a Guardian newspaper article. At the top, there is a navigation bar with 'Support the Guardian' (Fund independent journalism with \$5 per month), 'Print subscriptions', 'Sign in', 'Search jobs', 'Search', and 'International edition'. Below this is a menu with 'News', 'Opinion', 'Sport', 'Culture', 'Lifestyle', and 'More'. The article title is 'Spreading faster than ever': Bangladesh's tea pickers have world's highest rate of leprosy'. The sub-headline reads: 'Despite the WHO declaring it eliminated in 1998, thousands of tea pickers have caught the disease'. There is a photograph of a tea picker, Aloka Gonju, wearing a hat and a colorful shawl, holding tea leaves. Below the photo, the text says: 'Aloka Gonju, a tea picker in Sylhet, was diagnosed with leprosy a year ago. Now she can only pick leaves with her right hand, which limits how much she can earn. Photograph: Ruth Towell'. The article is by Thaslima Begum in Sylhet and Kaamil Ahmed, dated Fri 7 Apr 2023 06:00 BST. There are social media sharing icons for Facebook, Twitter, and Email. A small note says 'Global development is supported by BILL & MELINDA GATES Foundation'.

[Read the article from The Guardian newspaper](#)

A few months earlier, my presentation to the General Assembly

My **second report to the General Assembly** addressed on national legal protections available for persons affected by Hansen's disease and their family members. In the report, I ask: **how the recognition of persons affected Hansen's disease as entitled to the rights provided for in the Convention on the Rights of Persons with Disabilities is an important step in protecting this group of people?**

Based on that, I examine measures taken by States to recognize persons affected by Hansen's disease and their family members as persons who are entitled to disability rights and the barriers that hinder them from gaining access to those rights.

Apart from South Sudan, the remaining **22 WHO global priority countries for action against Hansen's disease have either ratified or acceded to the Convention on the Rights of Persons with Disabilities.** However, **a significant number of those States parties have not signed, ratified or acceded to the Optional Protocol.** This situation hinders persons with disabilities from gaining access to their right to an effective remedy and reparation.

While the majority of countries in which Hansen's disease is relevant have legal and regulatory frameworks in place that, in principle, recognize visible impairments, effective access to disability-related benefits remains largely unaddressed.



As part of my working methods, I **consulted persons affected by Hansen's disease** and their family members on issues such as self-identification and disability when preparing the report. Only four States actively contributed to the report, which reflects the extent to which persons affected by Hansen's disease and their family members are neglected by their own governments. **Twenty civil society organizations, working in 11 countries, submitted key information for the report. In total, 195 people from 23 countries, the majority being endemic, responded to my online questionnaire.**

When asked whether they self-identified as a person with disabilities, 74 per cent of the specific group of persons affected by leprosy responding to the questionnaire answered in the affirmative, as did 30 per cent of the family members of persons affected by leprosy. **While the majority of persons affected by Hansen's disease identify as persons with disabilities, others do not.** Discussion about the recognition of persons affected and their family members as persons with disabilities challenges any fixed definition of disability, as well as dichotomic frontiers between "disabled" and "non-disabled".

Acknowledgement of fluid, complex and evolving identities is key not only to avoiding any exclusion but also to preventing any labeling that goes against people's right to self-identification. As recognized in the Convention on the Rights of Persons with Disabilities, persons with disabilities are not a homogeneous group, but rather a very internally diverse one, as is the case with persons affected by Hansen's disease and their family members. Fluidity is at the heart of the preamble to the Convention, in which it is affirmed that disability is an evolving concept. However, binary definitions of "disabled" and "non-disabled" that do not recognize disability as a dynamic and evolving experience in people's lives are largely dominant.

While the majority of persons affected by Hansen's disease identify as persons with disabilities, others do not.

In total, **61 per cent of persons affected by Hansen's disease reported having been discriminated against on the ground of their impairments, as did 57 per cent of their family members.** A total of 36 per cent of persons affected by Hansen's disease mentioned not being recognized as a person with disabilities by doctors as a barrier to disability-related protection. Other 32 per cent said that they did not know about any possible benefits and 32 per cent complained about the absence of any benefit.

At the report, I affirm that

although progress has been made in the elaboration of national-level norms,

States must do more to effectively implement the provisions of the Convention on the Rights of Persons with Disabilities and I present a set of comprehensive recommendations on that regard.



- [!\[\]\(13dd0e1ab3baa23f7c1ed52b3eec2756_img.jpg\) Read the full report here](#)
- [!\[\]\(5ed985c65f50e5350eeeb77f03c2e095_img.jpg\) See the factsheet about my report here](#)
- [!\[\]\(9df44d2794f927e8a7eb6682863e4aa8_img.jpg\) Watch the full video on the report presentation](#)

Meetings in New York

During my travel to New York for the UN General Assembly, I had important meetings for raising awareness about issues experienced by persons affected by Hansen's disease and their family members. **I was especially honored to meet the UN Secretary-General António Guterres**, who listened attentively to the most critical problems impacting the lives of persons affected by Hansen's disease.



2nd Global Forum

Three years after the first meeting, in 2019, at Manila (Philippines), **representatives of persons affected by Hansen's disease gathered on the 2nd Global Forum of People's Organizations on Hansen's Disease, held in Hyderabad, India, last November.** At the meeting, I took stock of the advances since the first Global Forum and the effect that COVID-19 pandemic had on the activities of the People's Organizations.

In my speech, I highlighted the work of grassroots organizations during the pandemic. I acknowledge that **the relations among different organizations of persons affected by Hansen's disease grew stronger during the last years. The pandemic made everybody wish to be able to connect, to find out what their peers were doing and what were the problems people were facing. Many strategies were put in place to achieve that.**

Clearly, the COVID-19 pandemic also brought challenges - which I addressed in a specific report for the Human Rights Council, in 2021. The last years had a disproportionate impact on persons affected by Hansen's disease and their family members. In that report, I identified structural problems that were at the roots of many of the difficulties that persons affected by Hansen's disease and their families experienced.

Even so, the organizations were the first ones to sound the alarm about the disproportionate impact of the COVID-19 pandemic. They mobilized resources to ensure people's survival and were able to create monitoring systems. That is why I **claim there is a substantial discrepancy between such a huge accumulation of expertise and the various and persistent barriers that the organizations face in acceding funding and resources.**



[!\[\]\(feabb98897b440bc8695a03336a6e2df_img.jpg\) Watch my presentation at the Global Forum](#)

... which was held on the occasion of the 21st ILC

Just after the Global Forum, the 21st International Leprosy Congress (ILC) took place in the same city of Hyderabad, India. In my speech, **I presented evidence gathered by my mandate on progress and remaining challenges with regard to the elimination of discrimination** on the grounds of Hansen's disease over the past five years.

I looked over persistent discrimination in law, institutionalized and interpersonal discrimination, and violence. I also defended that stigmatization and discrimination of persons affected by Hansen's disease must be approached as interdependent social, economic, political and cultural issues.

I ended my speech at the International Leprosy Congress emphasizing **the urgency to promote a meaningful participation of persons affected by Hansen's disease in any process and decision-making that impacts their lives**. The elimination of Hansen's disease related discrimination is inseparable from the right to self-determination.

The travel to India was still an opportunity to participate in the **National Workshop for Leprosy Champions**, hosted by The Leprosy Mission Trust India and LEPRO Society. I felt deeply honored to meet such outstanding champions there. I was also happy to speak once more at the **ILEP's Member Assembly**.



[See some pictures of
the Global Forum and ILC](#)

NNN Conference

Another meaningful event that assembled grassroots, national and international organizations was the **13th Annual Neglected Tropical Disease NGO (NNN) Conference**, who took place in Kathmandu, Nepal, and also online. In its most recent edition, the conference focused on innovative solutions for health systems, aligned with Pillar 2 of the World Health Organization Road Map for Neglected Tropical Diseases (NTDs) 2021–2030.

The Global Appeal

was launched just before the World Leprosy Day

A few days before the World Leprosy Day (WLD), I also joined **the International Symposium at the Vatican and Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy.**

At my keynote speech, I stated that while progress on regard to the elimination of discrimination on the grounds of Hansen's disease is in course, **it still seems to be too slow for those who continue to face so many barriers to a dignified life.** We should bluntly acknowledge that despite our efforts, we are still not fulfilling people's rightful expectations.

The majority of good practices are developed and implemented by civil society organizations. Therefore, I suggest we learn from the organizations of persons affected by Hansen's disease, but also invest more on their development - both as individuals and collectivities.



I also **recommended the creation of a task force** from the organizations of persons affected by Hansen's disease that **could monitor all these processes at the national, local, but also international level** might be interesting. **A sort of a watchdog.**

Maya Ranavare, President of APAL India, claimed for **the establishment of a committee at the international level** to discuss issues relevant to persons affected by Hansen's disease and take follow-up actions.



I recommend the establishment of a task force or a watchdog for monitoring globally the human rights violations and abuses on the grounds of Hansen's disease.

- [🔗 Watch my keynote speech](#)
- [🔗 Watch the Global Appeal video](#)
- [🔗 Watch recommendations from organizations](#)

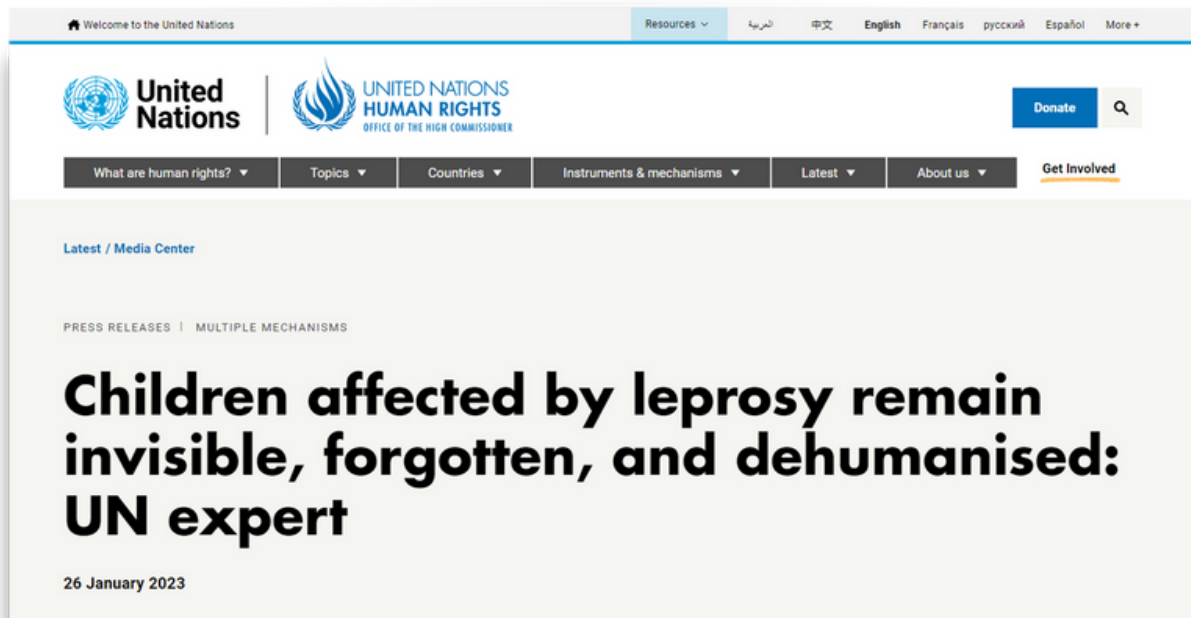
At WLD, my mandate statement was endorsed by UNICEF

My most recent statement on the World Leprosy Day, last January, addressed issues related to **children affected by Hansen's disease**. The statement was endorsed by the Committee on the Rights of the Child (CRC) and the United Nations Children's Fund (UNICEF).

Since the creation of my mandate in 2017, I have received numerous reports of children being expelled from schools, bullied, verbally and physically abused by family members, neighbors and schoolteachers. Moreover, stigmatization has long-lasting impacts over an entire lifetime. Girls affected by Hansen's disease are especially vulnerable to various forms of discrimination and violence.

Detection of Hansen's disease was significantly impacted by the COVID-19 pandemic, when the global rate for new child cases dropped from 7.9 to 4.5 per million child population. This is alarming because **under-detection leads to an increase in the rate of transmission and in the number of new cases among children**.

For those reasons, I urged States and other stakeholders, including the health industry, to ensure **child-friendly, gender-sensitive, disability-inclusive services**. Children affected by Hansen's disease must be recognized as rights-holders and their meaningful participation in relevant policy-making processes must be duly enabled.



[Read the statement for WLD](#)

... and I gave a speech for the Novartis Press Workshop

Still on the occasion of **World Leprosy Day**, I spoke in a press workshop held by Novartis. At the meeting, I remembered that the introduction of MDT, in the 1980s, brought great hope. It was then believed that it would not only provide a cure to the disease, but also eliminate stigmatization. However, bacteriological cure was not enough to eliminate deep-rooted discrimination against persons affected by Hansen's disease.

I clearly emphasized: Hansen's disease is much more than a disease. Hansen's disease became a label that dehumanizes those who are affected by it.

On World Leprosy Day, I also gave an interview to **El País Spain** and **BBC** published a report on the history and remaining challenges of Hansen's disease.



[🔗 Read my interview for El País \(in Spanish\)](#)

[🔗 Read the BBC report on Hansen's disease](#)

In March, I spoke to the

Committee on the Rights of Persons with Disabilities (CRPD)

when I stressed that **the recognition of persons affected by Hansen's disease and their family members as persons entitled to disability rights is essential to overcome medical and paternalistic approaches** to them.

I also mentioned that the need for a paradigm shift is not only urgent, but it is also imperative for organizations of persons affected by Hansen's disease.

And in May, to the

IDEA

On May 5th, I had the privilege to being welcomed at IDEA's gathering, where we discussed perspectives on human rights, progress, challenges and hopes.



A brand new group in Africa!

I was privileged to be invited to participate in the first meeting of the newly created **African Alliance against Neglected Tropical Diseases**. This is **the first regional alliance of organizations of persons affected by Hansen's disease and other Neglected Tropical Diseases**. This is a **massive breakthrough!**

I wish all the best of luck to the Alliance and all the grassroots organizations and activists who dared to dream big and positioned themselves as an important voice from the African region to the world!

[!\[\]\(fa6f3af6bfa46c5d4a2d362681095beb_img.jpg\) Read the full post](#)

Other organizations also made significant achievements

Maya Ranavare, president of **APAL India**, was awarded with a Durga Ratan Prize.

[Read the full post](#)

Lucrecia Vásquez, president of **FELEHANSEN**, in **Colombia**, won the Mujer CAFAM Prize.

[Read the full post](#)

Papa Mamadou Diagne, president of **MTN**, in **Senegal**, received a distinction from the Fédération Sénégalaise des Associations de Personnes Handicapées.

[Read the full post](#)

Losanganya Junior, president of **Dameda Foundation**, in **DR Congo**, had a private meeting with Pope Francis, as an extension of World Leprosy Day.

[Read the full post](#)


Faustino Pinto, **MORHAN Brazil** National Coordinator, made a speech discussing the risks and exclusion he faces as a person with disabilities associated with Hansen's disease for a series of videos produced by the UN Special Rapporteur on Human Rights Defenders Mary Lawlor.

[Read the full post](#)


In Brazil, **the Brazilian Federal Court System** decided that the national government is prohibited from using the word "leper" to refer to Hansen's disease. The decree maintains and reinforces a historical achievement of **MORHAN Brazil**.

[Read the full post](#)


The Leprosy Mission led a webinar, moderated by **Mathias Duck**, to debate partnerships among people's organizations and nongovernmental organizations.

 [Read the full post](#)

Subodha Galahitiyawa, an Associate Lecturer at **the University of the West of Scotland**, wrote an article for Taylor and Francis Online.


 [Read the full post](#)

YDTI, from **Indonesia**, launched its annual report in cooperation with **PerMaTa South Sulawesi**.


 [Read the full report](#)

Interviews

Peter Waddup, CEO **The Leprosy Mission England and Wales**, talks about the role of governments for the protection of persons affected by Hansen's disease.

 [Read the full interview](#)

Paula Brandão, PhD from **FIOCRUZ, Brazil**, explains about the impacts of her thesis on grassroots organizations.

 [Read the full interview](#)



Coming next...

20th to 22nd June

The **Bergen International Conference** on Hansen's Disease where I'll give a keynote speech.

[!\[\]\(a03a7eb2f4046e1d3c76772003e549ea_img.jpg\) Watch my speech at the Preparatory Webinar](#)

26th June

Human Rights Council

where I'll give my last presentation

