## Disabled Peoples' International (DPI) & Sasakawa Health Foundation (SHF)

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# Submission on draft General Comment on Article 27 of the CRPD

Since December 2019, the world has encountered one of the most critical pandemics in modern human history. Over the past year, a staggering number of people have been infected with the novel SARS-CoV-2 virus, many becoming critically ill and resulting in an increasing death toll around the world.

The coronavirus has shown that it does not differentiate between any member of society, infecting all sections of society equally. Unfortunately, the **socio-economic impact of the pandemic on marginalized, disadvantaged and fragile communities has been disproportionate** due to pre-existing attitudinal, environmental and institutional barriers popularizing it as the 'pandemic of inequality'. Several articles and studies by leading organizations and institutes have reported that marginalized and disadvantaged communities have been the most vulnerable not only because they are more susceptible to the coronavirus (due to their living conditions and lack of health and sanitation facilities, etc.) but more so because the economic impact of the pandemic has hit these communities the hardest. Loss of livelihoods and incomes have led to unemployment rates reaching an all-time high, depleting family resources, further widening the pre-existing inequalities and pushing these poor communities deeper into (extreme) poverty.

Persons with disabilities have been among the groups most subjected to the prevailing exclusion, discrimination and stigmatization shown through critical gaps at the level of emergency response programs, mainly in the Global South. As part of the response to the pandemic, providing economic resilience packages and work and livelihood opportunities to people with disabilities is critical in mitigating the crisis and ameliorating its effects on the community.

Given this scenario, CRPD Committee's General Comment on Article 27 (right to work and employment) that would provide guidance to States Parties to the Convention on the measures they should adopt to ensure full compliance with their obligations to respect, protect and fulfil the human rights of persons with disabilities, is welcomed.

However, along with providing insights into the challenges faced by persons with disabilities—challenges that institutionalize barriers to their full and effective participation and contribution as productive members of our communities—the Committee should also take into consideration the ground realities considering the impact of COVID-19 on the world of work and what it means for persons with disabilities. In doing so, it should give special attention to the have-nots within the disability community and 'neglected disabilities', as they may be called, which largely continue to remain invisible and seldom represented and recognized in disability policies and platforms.

Talking about neglected disabilities, it is no secret that **persons affected by leprosy** are one of the most stigmatized and discriminated communities in the world. Today, leprosy is curable with free and effective MDT treatment but, inspite of this, persons affected by leprosy continue to be ostracized and shunned by society, forcing them to live in isolation in leprosy colonies or self-settled communities that still exist in many countries.

India[1], which accounts for almost 60% of leprosy cases in the world each year, has around 758[2] leprosy colonies. While some people affected by leprosy are able to work in neighbouring villages and cities, getting stable incomes and providing education for their children, there are many who even after being cured of the disease (especially those with deformities) continue to face social stigma which prevents them from living outside the colony, thereby quarantining them for life and trapping them in a vicious cycle of struggle with poverty, unemployment, lack of basic amenities, insanitary conditions, overcrowding and malnutrition. Furthermore, participating organizations have reported that living outside the leprosy colonies, people affected by leprosy face harder living conditions than those living in leprosy colonies however, a comprehensive study is required to grasp the situation and needs of people affected by leprosy living in such conditions.

Fear of stigma also deters people from coming forward for diagnosis and treatment indirectly contributing to disease transmission and an increase in disabilities due to late detection. Having no or few support systems and with a high rate of illiteracy, livelihood opportunities are very limited for people affected by leprosy and they are mostly dependent on the informal sector doing odd manual jobs and many even turning to begging. Families of persons affected by leprosy also face an equal amount of stigma and discrimination—children are deprived of education or subject to bullying and rejection and in many cases these children have taken to rag picking / trash collection or assisting parents in begging for survival.

It is generally observed that persons with disabilities are the first to be let go from work when companies/government start budget-cuts. Due to the current pandemic, many workers with disabilities have been laid off and the concern is not only that there will be high unemployment of persons with disabilities but, also in some cases they are not able to access information on employment related programmes/initiatives[3].

Talking about persons affected leprosy, the economic impact of the pandemic has hit the community the hardest, pushing them further behind. Therefore, this vicious cycle of poverty and leprosy needs to be broken through economic empowerment for people affected by leprosy and their families. Unfortunately, the response of many of the governments has been limited to only health services such as detection camps, free MDT and other health related services. Though the scale of these government-run programmes is commendable and integral to eliminate leprosy, it is equally important to work on the socio-economic wellbeing of people affected by leprosy and their families to be able to end the stigma and discrimination in a true sense.

There are many (international and national) non-governmental organizations that apart from health services have also been working on social and economic inclusion of people affected by leprosy. However, there is very little work that is being done by States Parties in this area and it is generally seen as a part of a larger programme/scheme/initiative for disadvantaged communities. There are no initiatives that are targeted specifically towards the economic empowerment or mainstreaming of people affected by leprosy and their families into the society.

According to the data collated on available programmes and resources by the Global Partnership for Zero Leprosy's COVID-19 Emergency Advocacy Working Group and UN Special Rapporteur Alice Cruz, from 100+ persons affected and partners representing 24 countries, only one country (Myanmar) reported action that was taken by the government to specifically meet the needs of persons affected by leprosy while all others were general aid which was not equally accessible to

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[1] Due to limited time for collating information and case studies from all regions and the page limit for this submission, case studies and specific examples mentioned in this submission have been taken from only India which accounts for 60% of the Leprosy cases.

[2] According to the latest survey conducted by Sasakawa India Leprosy Foundation (SILF).

[3] A qualitative research study on the experience of persons with disabilities with COVID-19 by the Stakeholder Group of persons with disabilities for Sustainable Development.

all persons affected[4]. While temporary food aid was the most common there were few social protection measures such as cash transfers, or income replacement for lost livelihoods but these expired after the initial outbreak response and none of the countries reported that the needs of persons affected are being entirely and adequately met by governments and NGOs and there have been concerns for the long-term effects of the current planning and social protection measures for persons affected by leprosy, which do not seem to be adequate for the future.

Some examples of Livelihood initiatives taken by some of the organizations in India:

1. ***Sasakawa - India Leprosy Foundation (SILF)*** has been running over 350 projects in India empowering over 2000 beneficiaries in diverse sectors like livestock, agriculture, food processing, retail & wholesale. In the current financial year, 234 families have been provided with seed capital, training & market linkage support for entrepreneurship. SILF has also been running learning centres for children from Leprosy colonies. Furthermore, in the past few years, 30 girls currently working as nurses in reputed hospitals have benefitted from scholarships, over 200 students have benefitted from His Holiness Dalai Lama Sasakawa Scholarships and over 800 youth have enrolled in S-ILF's Skill Development Program—with 90 percent finding employment after completion of the course. S-ILF has also promoted self-help groups (SHGs) in the state of Bihar and linked these to the State Rural Livelihood Mission which envisages policy guidelines to make SHGs of Persons with Disabilities and provide them capitalization and other support for their livelihood requirements/micro enterprises. During the pandemic, with education shifting from classrooms to online, the children from the leprosy colonies could not cope up as most of them did not have laptop/smart phone or internet connection. While providing counseling to them, SILF also provided laptops wherever possible and distributed educational material to children in the leprosy colonies with the support of Sasakawa Health Foundation (SHF).
2. ***Saksham Kushthanteya Swabhimani Sanstha (SKSS)***, set up in 2019 with technical support from ***ALERT-INDIA Mumbai*** has been mobilizing resources for livelihood support for persons affected by Leprosy in the colonies and is also working on skill development / capacity building / policy advocacy plans.
3. ***Atma Swabhiman*** in India has been organizing and motivating women affected by Leprosy towards the formation of SHGs and facilitating them by linking them with the National Urban Livelihoods Mission (NULM). The organization has also collaborated with Tata Steel Rural Development Society to provide Micro-Cellular Rubber (MCR) footwear to people affected by Leprosy and has also been liaising with the Micro, Small & Medium Enterprises (MSME) department of Government of India to provide livelihood support for people affected by Leprosy.

A direct result of limited access to education can be seen as a significant disadvantage upon entering the job market. Therefore, a person affected by Leprosy who has far less chance of education thus has less chance of employment. Due to the stigma and discrimination, persons affected by leprosy and, in some instances, their family members, are also denied admission to educational and training institutions which hinders their access to professional training or educational qualifications that are a prerequisite to access employment opportunities. As a result, in some cases, family members of persons affected by leprosy tend to forge addresses or lie about their identity in order to go to a school, college or vocational training institute.

Further, just like with other laws, existing employment laws to terminate the employment of persons can be used to discriminate against people affected by leprosy. The Industrial Disputes Act, 1947 in India which although it does not mention leprosy, provides for termination of services on grounds of continued ill-health that does not constitute retrenchment[5]. Though there are no available statistics on the issue of violation of rights to work and employment of persons affected by Leprosy, considering the prevailing social stigma, it is very difficult to infer that issues of violation of rights are not encountered by people affected by leprosy at workplaces. However, the lack of quantitative evidence can be attributed to the lack of research on the impact of socio-economic indicators as well as low reporting by people affected by leprosy themselves and their family members including instances where they invariably tend to conceal their identity or diagnosis at the workplace.

Furthermore, even if issues of discrimination at the workplace do come up, they are generally brushed under the rug as the victims have no knowledge of their rights or in some cases they are

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[4] https://zeroleprosy.org/wp-content/uploads/2020/09/COVID_Persons-affected-fact-sheet.pdf

[5] https://lawcommissionofindia.nic.in/reports/Report256.pdf

resolved through local interventions with efforts from advocacy forum / community members / non-governmental organizations. Victims in such cases very rarely take legal recourse to avoid additional costs or unnecessary trouble due to their socio-economic conditions. It has also been observed by participating organizations that cases of stigma and discrimination are relatively more in areas where there are / were leprosy colonies. However, to estimate the quantum / cases of rights violations there is an imperative need to undertake a survey among people affected by Leprosy.

**Below are some case studies from India of people affected by leprosy facing discrimination and stigma at workplace and in accessing work, employment and livelihood opportunities including the impact of COVID-19 and interventions by non-governmental organizations leading to good practices.**

***Case Study 1:*** Anuradha Arun Sonkar from Antargaon Tola village in Maharashtra was working as a cook at Navabharat Vidyalaya under primary school mid-day meal programme since 2013 faced termination on ground of history of Leprosy even though she had been cured after taking MDT after her diagnoses in 2010. The school authorities planned to give her a letter to undergo medical check-up at Chandrapur but, when Anuradha informed a Primary Healthcare Centre about her situation, a hospital staff member spoke to the school authorities. Though the matter did not go forward, people started asking children to stop eating the food cooked by her and fabricated some other reason to remove her from work. It was only after Anuradha went on a hunger strike that there was a meeting with the School Management and Committee and she was re-instated. However, some people were still angry and went on hunger strike to oppose the decision, but Anuradha fought back and went to court and got a stay order.

Similar to Anuradha, there was another case of a women working as helper in Anganwadi (pre-school class) with foot ulcer and hand wounds that was going to be removed from her job on strong demand from the parents of the children but, due to the intervention of LEAP HRBA project team, she was able to keep her job and sent on leave till her wounds were healed. Also, the team helped a male school staff member with chronic multiple ulcers who was issued a notice for medical fitness with the intention of initiating the process of declaring him unfit for the job. Members of an advocacy forum (including community members / media persons / local medical practicing doctor, etc.) took the lead and advocated the case with school functionaries successfully, and the case was rested[6].

***Case Study 2:*** With no educational qualifications and no hope of secure job, Sarothi Devi, who was diagnosed with Leprosy at the age of 9, survived by begging on the streets near Bankati Leprosy colony in Jharkhand, India for the past 20 years along with her husband. They were also using part of their income from begging for their children's education. Unfortunately, at the start of the COVID-19 pandemic in February 2020, her husband went to beg as usual; however, he did not return home and the family does not know whether he is dead or alive. If losing her husband was not enough, Sarothi Devi lost her source of income due to the pandemic and the family had to go many days and nights with no or little food to eat. Going through hardships and struggling to make ends meet, Sarothi Devi thought of committing suicide. However, thinking about her young children and with the help of rations from Atma Swabhiman including school fees for her children, she survived. Unfortunately, the income from begging is not enough for the survival of the family. Consequently, she has also started working sometimes in the coal mines. Also, her son has left home and has started working as a contract labourer in another state, Tamil Nadu[7].

**Fig 1: Sarothi Devi with her children**

***Case Study 3:*** Dhiraju Singh, who was diagnosed with leprosy at the age of 8, lives with his wife who is also a person affected by leprosy. Many people in their colony beg on the streets. However, he wanted to live a life of dignity and found a job for himself and his wife at the rehabilitation center earning between Rs. 1500 to 2000 per person subject to availability of work. Since they have no children or family, this small amount was sufficient for their daily survival. However, the pandemic took away their limited source of income and even after the end of lockdown, there was only limited work at the rehabilitation center. Because of this, there came a point where he thought he would have to go begging on the streets like others—something which he promised he would never do. However, because of the support of Atma Swabhiman he received rations and they also encouraged him and his wife to start some livelihood activity. Although they were initially hesitant due to deformities and having worked only at the rehabilitation centre, with some financial assistance from Atma Swabhiman, they started selling vegetables. However, Dhiraju Singh only helps his wife on the sidelines but does not sell the vegetable directly as he has visible deformities and people would not buy vegetables from them if they come to know about their condition. Since his wife has deformities only in the feet, it is easier for her to conduct the business and interact with the customers. But, inspite of this, the couple is happy with their daily earning of Rs. 90 and looking at scaling their vegetable business[8].

**Fig 2: Dhiraju Singh (left) and his wife selling vegetables (right)**

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[6] Case study provided by SKSS (Reference LEAP HRBA project by ALERT-INDIA, Mumbai in Chandrapur & Gadchiroli districts, Maharashtra-India; HRBA-Human rights Based Approach)

[7] Case study provided by Atma Swabhiman.

[8] Ibid.

***Case Study 4:*** Rani, a 21-year-old girl from Tahirpur leprosy complex in New Delhi, India led a very difficult life. However, when she heard about the 6-month Emergency Medical Technician course being sponsored by S-ILF, she enrolled herself and completed the course with flying colours. She is currently working with CATS Ambulance services and earning around Rs. 17,000 per month and supporting her two younger brothers in completing their studies as well as completing her studies through distance mode. During the pandemic, Rani fearlessly took the responsibility and attended every call and she was also chosen to receive special training to handle Corona cases[9].

***Case Study 5:*** Suvajit from Monipur Leprosy Colony, Adra in West Bengal experienced severe financial issues and his parent's struggle in the absence of good employment opportunities at the leprosy colony. Suvajit applied for the His Holiness Dalai Lama Sasakawa scholarship (HHDLSS) and with his academic record and exceptional performance he was selected for the scholarship and opted to pursue Hotel Management from NSHM Institute of Hotel Management in West Bengal. On completion of his course, he was offered on-the job training by Oberoi-Trident Nariman Point, Mumbai with a monthly salary of Rs 14,000 and continued to work at the Oberoi Trident. However, due to the pandemic, he was laid off and had to go back to the leprosy colony.

Fig 3: Food being distributed from the community kitchen

During the lockdown he witnessed the plight of the community who struggled to put food on the table for their families. Suvajit came across a student group from Kolkata who were supporting the marginalized members of the society and together with them started a community kitchen in the colony which ran for 4 months helping over 200 people (80% of the colony population) on a daily basis. In addition to this, identifying the need for education of children in the colony who had no arrangement for on-line classes, they initiated Prithvi Pathshala/classrooms, to cater to the needs of the students from nearby 3-4 villages conducting classes twice a day for 4 hours. At the same time, Suvajit also kept applying for jobs and will be soon joining a Cruise Line operating from Mumbai. Suvajit's dedication and success story has brought a new wave of hope in leprosy colonies for the future of children of people affected by leprosy[10].

Fig 3: Prithvi Pathshala being run in Monipur leprosy

Both the CRPD and the SDGs recognize the importance of education for work and employment opportunities, including vocational and continuing training. Although lower education levels often achieved by persons with disabilities impact access to employment, there are also other factors that appear to play a significant role in limiting job opportunities including discrimination, stigma, negative attitudes, lack of accessible transportation to get to work, and inaccessible workplaces with limited availability of accommodations for persons with disabilities[11].

Leprosy being specifically identified as one of the 21 disabilities under the **Right to Persons with Disabilities (RPWD) Act 2016 in India**[12] and the definition of disability based on Article 1 of the CRPD under **The Discrimination against Persons with Disabilities Prohibition Act 2018** in Nigeria[13], people affected by leprosy are entitled to claim benefits under various schemes and provisions designed for people with disabilities including those that support their right to work and employment—such as 4% reservation in educational institutions, 5% reservation in government jobs identified for people with disabilities, provision of reasonable accommodation and right to legal representation, among others.

However, when it comes to persons affected by leprosy, there are two major issues in these laws that hinder them from accessing benefits. Citing the RPWD Act 2016 in India, the first issue is the *terminology* used, which recognizes only "Leprosy cured person" and not person affected by Leprosy. ("Leprosy cured person" means a person who has been cured of leprosy but is suffering from (i) loss of sensation in hands or feet as well as loss of sensation and paresis in the eye and eye-lid but with no manifest deformity; (ii) manifest deformity and paresis but having sufficient mobility in their hands and feet to enable them to engage in normal economic activity; and (iii) extreme physical deformity as well as advanced age which prevents him or her from undertaking any gainful occupation, and the expression "leprosy cured" shall be construed accordingly. The second issue is the *assessment and certification* of disability which recognizes provisions under

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[9] Case study provided by SILF

[10] Ibid.

[11] https://social.un.org/publications/UN-Flagship-Report-Disability-Final.pdf

[12] http://disabilityaffairs.gov.in/content/page/acts.php

[13] https://afri-can.org/wp-content/uploads/2019/08/Nigeria-Bill-2018-Harmonised.pdf

the law for leprosy-cured persons with benchmark disabilities ("person with benchmark disability" means a person with not less than 40% of a specified disability where specified disability has not been defined in measurable terms and includes a person with disability where specified disability has been defined in measurable terms, as certified by the certifying authority). Unfortunately, most of the persons affected by leprosy who face severe nerve damage (loss of sensation) related disabilities rather than locomotor related disabilities (deformity hand and feet, etc.) cannot fulfill the criteria for >40% disability and hence lose out on several benefits.

Given the deformities of hand, feet and eyes, persons affected by leprosy are also unable to take advantage of government benefits that require biometrics for identity and social entitlements. Further, leprosy colonies which are built on the outskirts of the cities/villages on government land are considered illegal even though people affected by leprosy have been residing in these colonies for generations which further acts as a hindrance in many circumstances. There are very few instances where residents have been given land-ownership while the majority of the residents are constantly under fear of eviction by the State.

In India, the Unique Identification Card (AADHAR) is used by the government to provide direct cash transfers and other benefits directly to the beneficiaries. Unfortunately, because of the required biometrics, many people affected by leprosy could not get these cards as they could not give thumb impressions and eye scans due to deformities. ***Association of Persons Affected by Leprosy (APAL)*** and the ***National Centre for Promotion of Employment for Disabled People (NCPEDP)*** brought this issue to the attention of the concerned Department under the Ministry of Social Justice & Empowerment who in turn wrote to the issuing authority (UIDAI) and resolved the matter[1].

Living on the outskirts of the cities/villages in leprosy colonies, people affected by leprosy and their families have to travel long distances and therefore, rely on local transportation for work, education, skills training, livelihood options and accessing healthcare services and benefits. However, due to the stigma associated with the disease, people affected by leprosy continue to face the possibility of restrictions on movement and public transportation because of prevalent laws such as the **Metro Railways (Carriage and Ticket) Rules 2014 in India** which has provisions under which the driver/conductor can ask people affected by leprosy to get off buses and trains unless they are able to provide a certificate declaring them leprosy cured. Also, some acts can be easily misused to discriminate against people affected by leprosy such as the **Indian Railways Act,** which does not have any direct mention of leprosy but provides for discretionary power with the railway officer to remove anyone from a train if he feels the person is suffering from a contagious disease.

In India, the **Maharashtra State Transport** has been providing leprosy cured persons with 75% concession on their buses; however, this is limited to leprosy cured only and only to State-owned transport buses, so is limited in its scope and benefit.

Deep-rooted social and religious beliefs have continued to perpetuate the stigma and discrimination faced by people affected by leprosy to such an extent that they are backed by a number of laws that contravene the States Parties obligations under the CRPD and contradict the Resolution on the Elimination of Discrimination against Persons affected by Leprosy and Their Family Members unanimously adopted by the UN General Assembly in 2010 and accompanied by Principles and Guidelines (although not binding) modelled on the CRPD Convention.

There are around 22 countries and 130 laws and provisions (related to segregation/separation, immigration, transportation, education, etc.) that continue to indirectly hinder the participation of people affected by leprosy in work and livelihood-related activities while around 25 of these laws and provisions have direct employment-related discrimination[14]. In a number of laws relating to statutory universities in India, people affected by leprosy are disqualified from becoming members

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[14] https://ilepfederation.org/discriminatory-laws/

of academic councils or governing boards while several other laws deny them from holding public office, or contesting local body elections.

**Some examples of discriminatory laws and provisions**:

**Nurses and Midwives Act, 1953 in India** has provisions under the law that calls for disqualification for being or continuing as a member of the council if affected by leprosy. **Andhra Pradesh Co-Operative Societies Act, 1964** disqualifies a person from being or continuing as a member of the committee if suffering from leprosy. **Pakistan Fish Inspection and Quality Control Act, 1997** states that no Person who is suffering from leprosy, tuberculosis, polio or such other contagious diseases, shall handle, carry or process fish or work in a fish processing and packing plant or establishment. **Alien Occupation Act, B.E. 2551 (2008) in Thailand** excludes people diagnosed with leprosy from obtaining work permits. If an applicant is diagnosed with leprosy with no severe active/complications, a work permit will be granted along with treatment. If severe active/complications are found, a work permit is denied and treatment is provided before deportation.

A writ petition (1151/2017) filed by **Vidhi Centre for Legal Policy versus Union of India** seeks to repeal 119 central and state laws that violate the fundamental rights of persons affected by leprosy under Articles 14, 19 and 21 of the Indian Constitution. Since 2017, 13 discriminatory laws have been repealed or amended but there still remain 106 discriminatory laws which, as pointed out by the Supreme Court of India, are in contravention of India's obligations under the UN CRPD.

The Supreme Court of India in 2018 gave directions in its judgment in **Pankaj Sinha vs Union of India** and others [Writ Petition (Civil) No.767/2014] to address the various forms of discrimination against persons affected by leprosy. These directions included leprosy awareness programs, seminars at all levels to hear the views of persons affected by leprosy, prohibition of discriminatory behavior within the health services and education services, ensuring available supply of leprosy medication, free supply of protective footwear, development of comprehensive community-based rehabilitation programs, and attention to ensure that persons affected by leprosy are issued the correct identity and social entitlement cards.

Thus, to ensure access to work and employment opportunities for people affected by leprosy, it is important to ensure that they are qualified; therefore, it is important to ensure people affected by leprosy and their family members can access education and vocational training. However, to ensure that they are able to take advantage of education facilities, it is equally important to ensure accessibility (physical environment, transportation, digital). For that to happen, States Parties need to ensure good policies and legislation are in place inorder to ensure government departments, educational institutes and universities, private organizations and corporates are following accessibility standards and guidelines ensuring quality education and equal employment opportunities for persons affected by leprosy. However, this is possible only through advocacy, sensitization and awareness generation among the relevant stakeholders and the public in general. Therefore, the issue of employment needs a holistic approach as Article 27 is interrelated with various other provisions and Articles under the CRPD.

However, despite international commitments and legislations, the ground realities experienced by persons affected by leprosy have not changed much. Thus, keeping in consideration the spirit of 'Nothing About Us, Without Us' and strengthening the call for 'Leave No One Behind', DPI, in partnership with SHF and with inputs from organizations of persons affected by leprosy (Atma Swabhiman, Disadvantaged People's Association (DAPA) Bangladesh, Ethiopian National Association of Persons Affected by Leprosy, Gerakan Peduli Disabilitias Dan Lepra Indonesia (GPDLI)/Indonesia Leprosy and Disability Care Movement, IDEA Nepal, IDEA Nigeria, NCPEDP, S-ILF, SKSS, TLM Nigeria & TLM International/UK) and disability inclusion expert (Mr. Pradeep Bagival, UNDP Laos), is making the following submission on behalf of people affected by leprosy and their families with regards to their right to work and employment.

## Recommendations

While the disability movement and the CRPD Committee has been well-intentioned in representing a unified cross-disability voice, it would be imperative to also acknowledge the **existence of inequalities within the disability sector** by specifically mentioning disabilities that require special attention due to years of (unintentional) neglect within the community, especially with regard to **persons affected by leprosy**. Streamlining neglected disabilities by making structural modification throughout the document would permit more space for elaboration on States' obligations, which would ultimately lead to the inclusion of more concrete measures for improved guidance to States Parties and other stakeholders on upholding the rights to work and employment of neglected disabilities, particularly **leprosy**.

The Committee has rightfully noted and as mentioned above, **right to work and employment cannot be discussed in silos**. It is imperative to take into consideration other aspects and rights which are necessary for a person's right to work and employment, such as educational and training opportunities, right to freedom of movement and transportation, land rights, appropriate use of language, raising social awareness on the capabilities of persons affected by leprosy, increased accessibility of the physical environment, transport, information and communication, and other welfare measures such as concessions during treatment to account for additional disability/medical costs to ensure right to equal pay for equal work, all of which will optimize opportunities for persons affected by leprosy to participate in the labour market.

In order to ensure the right to work and employment for people affected by leprosy, the Committee should stress both **the legal aspect** (amendments to the legal provisions to protect the rights of persons affected by leprosy) and **the social aspect** (awareness, education and livelihood opportunities, etc.) for elimination of stigma and discrimination faced by people affected by leprosy and their families and the Committee should also stress the need to integrate the leprosy sector into the larger disability movement by integrating their advocacy initiatives.

The present submission makes the following proposals toward this end:

- The Committee should **call for repeal of ALL discriminatory laws and provisions against persons affected by leprosy** and recommend States Parties to provide **adequate protection of right to work and employment** (equal opportunities and equal remuneration for work of equal value, reasonable accommodation, safe and healthy working conditions, including protection from harassment, and redress of grievances) for persons affected by leprosy under the national disability legislations and to ensure anti-discrimination commissions under the national disability laws take measures to **identify and address discriminatory practices** not only in employment/labour laws (recruitment, hiring, promotion, salary, continuance of employment and career advancement) but in all other aspects (transportation, segregation, education, independent living, accessibility, health insurance and rehabilitation services, etc.) as they are interrelated and can prevent persons affected by leprosy from having access to decent and full employment. A case in point is India, which has 60% of the global burden of leprosy and also the majority of the discriminatory laws (106) in force. The Committee should make special recommendations for India to repeal all 106 discriminatory laws and provisions within a time frame. State Parties should also include **special measures to ensure no existing laws are misused** to discriminate/terminate employment on grounds of the disease and associated stigma.
- The Committee should **discourage the use of the term 'leper' and other such synonymous terms** in use in many countries, as they have negative connotations and perpetuate stigma and discrimination hampering all efforts of inclusion of people affected by leprosy in the society. States Parties should **broaden the scope of the terminology** from 'Leprosy cured' to **include 'all categories of persons affected by leprosy'** into the disability narrative and legislation.
- The Committee should recommend States to ensure that **certification boards for issuing disability certificate include a leprosy expert** and that **loss of**

**sensitization/nerve damage is taken into consideration while making the assessment** for people affected by leprosy.

- The Committee should **call for affirmative action** to complement anti-discrimination legislations and recommend States Parties to **earmark quotas in employment specifically for persons affected by leprosy** in government establishments or provide for alternate employment/livelihood opportunities. Case in point, the Karnataka provincial government in India has quotas for people affected by leprosy in government jobs. In countries where such legislation exists in the public and/or private sectors, the State should **ensure its implementation with an effective evaluation system** throughout the career development of employees affected by leprosy and **provide incentives and other measures to the private sector to encourage employment** of persons affected by leprosy.
- The Committee should recommend State Parties to **design special programmes/initiatives and financial assistance** (concessions/subsidiaries/microcredit) targeted specifically towards persons affected by leprosy and their families in leprosy colonies, given that access to inclusive education and vocational training go a long way in ensuring livelihood opportunities for persons affected by Leprosy. Such programmes and assistance should be part of national educational policy, vocational training and rural/urban development programmes and livelihood missions including Micro, Small and Medium Enterprises schemes (co-operatives, cottage industry, agricultural, craft or other activities[15]) for self-employment and entrepreneurship development, including providing information on how these can be accessed. These programmes should **ensure equal participation of women in livelihood opportunities and children in education and scholarships from Leprosy colonies**. Further, State Parties should be urged to address discriminatory practices and **encourage private sector and civil society organizations to include persons affected by leprosy in schemes** such as micro finance, self-employment and business development services.
- State Parties must **ensure proper budget allocation at national and subnational levels, with targets, indicators and benchmarks**[16] within the context of the realization of the 2030 Agenda for Sustainable Development (especially Goal 8 on decent work and employment and Goal 4 on quality education).
- The Committee may kindly recommend, in line with the UN Disability Inclusion Strategy, the **UN Country Teams to ensure that the national governments address discrimination** faced by persons affected by leprosy **and create employment opportunities through inclusive policies and programmes**.
- The Committee should recommend States Parties to **ensure legal empowerment** of persons affected by leprosy by guaranteeing them critical rights such as legal rights, business rights, property rights, labour rights and access to justice which could result in alleviation of poverty and create access to decent livelihoods. In line with this, the States Parties with active leprosy colonies should facilitate access to housing by taking special measures to **handover land-ownership/property titles to persons affected by leprosy** residing in these colonies within the next 5 years.
- **There needs to be increased attention to addressing the stigma and discrimination** faced by persons affected by leprosy and mainstreaming their specific needs across the full text, in particular for supporting those with small businesses and livelihood initiatives and having difficulties and challenges selling their produce/products outside their community due to the stigma and the lack of awareness on the transmission of the disease. In addition, **persons affected by leprosy should be included in the consultation**

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[15] https://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_103529.pdf

[16] https://documents-dds-ny.un.org/doc/UNDOC/GEN/G20/103/91/PDF/G2010391.pdf?OpenElement

**process for policy-making** and **represented in all disability committees and platforms,** thus furthering the 2030 Agenda for Sustainable Development built upon the recognition that development is not only about transforming the material conditions of people in disadvantaged circumstances, but also implies to providing them with a voice and choice[17].

- The Committee should emphasize the importance of data collection in facilitating the twin-track approach in enhancing remedies for intersectional and multiple discrimination and violations of rights to which persons affected by leprosy are subjected and to carry out evidence-based analysis and programmes; States should ensure that a database of available information and **disaggregated data on persons affected by leprosy and employment is developed** and available in an accessible format[18].
- States Parties should **ensure reform and reconstruction of social protection policies & emergency response programs according to the principles of social equality & inclusion** with special attention to communities of persons affected by leprosy that have been leading a life of social exclusion in leprosy colonies even before the emergency. Further, **States Parties must scale up social protection measures** – providing social safety nets and cash transfers, protecting jobs, working with employers to support working parents, and prioritizing policies that connect families to life-saving health care, nutrition and education[19]. The national socio-economic response of leprosy endemic countries to COVID-19, in particular, should **consider persons affected by leprosy as one of the most vulnerable groups** and have access to financial and other benefits provided by the respective governments so that inequality is not perpetuated.
- States Parties should **provide relevant concessions and monetary benefits for undergoing treatment, health insurance and counselling, Micro Cellular Rubber (MCR) footwear, and pension** (minimum USD 85 per month) for persons affected by leprosy who are not able to work due to age, ill health and disability, and in extreme poverty, given the interlinkage of leprosy and poverty and the additional cost of the disease and disability.

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[17] https://www.ohchr.org/Documents/Issues/Leprosy/SR_leprosy_Open_letter_22May2020.pdf?fbclid=IwAR27vhN6FGp4FlgcmoNOfJEqEFfA0eTvfgK0ul7Ar9dP9ggYScbr5kzMa0g

[18] https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/10/UN-flagship-report-on-disability-and-development.pdf

[19] https://www.unicef.org/press-releases/dont-let-children-be-hidden-victims-covid-19-pandemic