

# RESPONSE TO LIST OF ISSUES REGARDING PERSONS AFFECTED BY LEPROSY IN BANGLADESH

Submitted for the consideration of the 23<sup>rd</sup> Session of the CRPD Committee

Submitted by:

**The Leprosy Mission International – Bangladesh (TLMI-B),  
Protibondhi Nagorik Shangathaner Parishad (PNSP) and  
Advancing Leprosy and disadvantaged peoples Opportunities Society (ALO)**

(The submission may be posted on the OHCHR website)

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This submission is made by a consortium of three organisations in Bangladesh that actively advocate for the fulfilment of the rights of persons affected by leprosy.<sup>1</sup> In each of these organisations, persons affected by leprosy play a leading role of a significant participatory role in organisational decisions. ILEP, a federation of anti-leprosy agencies based in Geneva, has supported the process.

## 1. Contributors

**The Leprosy Mission International Bangladesh (TLMIB)** is one of a global network of members of an international Christian non-government organisation with 143 years of history of working for and with persons affected by leprosy. Its vision is ‘leprosy defeated, lives transformed’. The organization involves persons with leprosy related disabilities in advocacy to realize their rights guaranteed under the CRPD and to end the stigma and discrimination that prevent them from enjoying human rights on an equal basis with others.

**Protibondhi Nagorik Shangathaner Parishad (PNSP)** is a national network for coordinating disabled people’s organizations of Bangladesh. In order to establish rights and develop the conditions of persons with disabilities, PNSP extends policy support to the Ministry of Social Welfare and related ministries. PNSP is the member of National Monitoring Committee on the implementation of CRPD under the Ministry of Social Welfare. It is the sole representative organization from Bangladesh in Disabled People’s International (DPI), a network of organizations from 155 countries.

**Advancing Leprosy and disadvantaged peoples Opportunities Society (ALO)** is an organization of people affected by leprosy and disability and works to establish rights and entitlements, create employment opportunities, ensure access to good quality care, and foster economic and sustainable development of disadvantaged people, including people affected by leprosy and disability, in Bangladesh. ALO represents more than 1600 Self-Help Groups (SHGs) and 89 Federation from 20 districts of Bangladesh. It supports empowerment, creating awareness, increasing knowledge, building capacity, developing skills and influencing confidence to enable quality lives for the affected people.

## 2. Executive Summary

Persons affected by leprosy often face discrimination on account of the stigma associated with leprosy. They find it difficult to realize some of the human rights guaranteed under the CRPD. They

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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.

are often refused treatment in general hospitals. A majority of women affected by leprosy experience mental health problems causing psycho-social disabilities. Lack of awareness about human rights has led to disempowerment and marginalization of this minority group within the disability population in Bangladesh. There are instances of divorce being initiated by the spouses of persons with leprosy related disabilities, and often stigma attached to their medical condition makes it difficult to seek employment and vocational training.

Leprosy should be explicitly mentioned in the Anti-Discrimination Bill coming before parliament. Social Protection schemes should specifically target persons with leprosy related disabilities, and there is a need for awareness campaigns, complaints systems and other mechanisms to combat stigma in the communities, so that persons with leprosy related disabilities are able to enjoy social and cultural rights on an equal basis with other citizens. It is equally important to include persons with leprosy related disabilities as a defined group for data collection until such time there is reduction of stigma against them, and to ensure that Government has mechanisms to hear the voice of persons affected by leprosy. Effective implementation of the Principles and Guidelines to eliminate discrimination against persons affected by leprosy and their family members is one of the overarching recommendations, to ensure protection and promotion of the rights and dignity of persons with leprosy related disabilities within the framework of the CRPD.

### **3. Background and context**

According to WHO around 210,671 new cases of leprosy were reported from 150 countries in the year 2017<sup>2</sup>. However many millions are thought to go unreported<sup>3</sup>. An estimated 20-25% of persons affected by leprosy experience disability. <sup>4</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. Bangladesh ranks fifth in the world with over 4,000 cases new cases diagnosed annually<sup>5</sup>. Acute stigma attached to this ancient disease has prevented early detection and prompt treatment of the disease, leading to disability. While some estimates suggest that over 3 million people are living with leprosy related disability globally, the actual figures could be much higher. In Bangladesh, leprosy affected persons refuse to be identified due to the fear of stigma, and disability stakeholders often exclude persons with leprosy related disabilities in their policies and programmes leading to further exacerbation of the exclusion experienced by them.

Since historical times, leprosy has been feared and misunderstood in Bangladesh. A major reason for this is the deep-rooted myths and misconceptions that revolve around the understanding of leprosy as a disease both in the past and even today. Although leprosy is not highly contagious, it is often perceived as being contagious, hereditary and received as a divine punishment<sup>6</sup>.

After Bangladesh declared elimination of leprosy, government attention towards leprosy reduced and the situation of persons affected by leprosy related disabilities remains unchanged in the leprosy prone districts. Persons affected by leprosy are often discriminated against in educational institutions, transport services, restaurants, religious places and within the family.<sup>7</sup> There are still instances where persons with leprosy related disabilities are addressed using derogatory terms such as 'lepers' which reinforces existing stigma against them.

### **4. Views of TLMIB, PNSP and ALO**

This section contains the views and recommendations of the three contributor organizations to the Bangladesh List of Issues CRPD/C/BGD/Q/1.

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<sup>2</sup> WHO Weekly Epidemiological Record, 31<sup>st</sup> Aug 2018

<sup>3</sup> <http://journals.plos.org/plosntds/article?id=10.1371/journal.pntd.0003658>

<sup>4</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/)

<sup>5</sup> WHO-[http://www.searo.who.int/bangladesh/areas/mycobacterial\\_disease/en/](http://www.searo.who.int/bangladesh/areas/mycobacterial_disease/en/)

<sup>6</sup> Progress report on the implementation of the principles and guidelines: A/HRC/AC/17/CRP.1/29<sup>th</sup> July 2016

<sup>7</sup> Progress report on the implementation of the principles and guidelines: A/HRC/AC/17/CRP.1/29<sup>th</sup> July 2016.

#### 4.1 Equality and non-discrimination (art. 5)

Paragraph 3 of List of Issues

We appreciate the initiative of the Law Commission and National Human Rights Commission on drafting the Anti-Discrimination Bill. But it is essential for leprosy to be included as a disease into the bill, because people affected by leprosy are among the most discriminated against in Bangladesh. People affected by leprosy experience discrimination and isolation e.g. divorce, isolation from family, terminated from job etc. Basic leprosy services are available at the primary level government health point but complication management services need to be strengthened and made available at secondary level government health points (medical college and hospital, leprosy specialized hospital). Our honourable Prime Minister Sheikh Hasina said at the National Leprosy Conference held on 11 December 2019 not to discriminate people affected by leprosy.

***We believe it will contribute to attaining zero discrimination under “Zero Leprosy Initiative by 2030” initiated by the Government if the Government explicitly include leprosy as one of the diseases referred to in the Anti-Discrimination Bill, this will enshrine in law that people affected by leprosy have equal access to healthcare and other entitlements.***

#### 4.2 Awareness-raising (art. 8)

Paragraph 7b of List of Issues

Successfully organizing the National Leprosy Conference on 11 December 2019 and “Zero Leprosy Initiative by 2030” declared by the honourable Prime Minister at the event is a great milestone. This has drawn the attention and built awareness of politicians, health professionals and mass people on leprosy. But still media and grass root level Government health staff can play a major role in building leprosy awareness at community level, which would contribute towards zero discrimination.

***As the Government is positive towards disseminating information to general public, prioritizing leprosy greater efforts could be taken to extend leprosy awareness at every level through engaging frontline government health workers and media for increasing self-reporting and early new leprosy case finding would result reduction in the burden of disability due to leprosy.***

#### 4.3 Respect for home and the family (art. 23)

Paragraph 21 of List of Issues

In 2011 the Government repealed the Leper Act 1898 under the leadership of honourable Prime Minister Sheikh Hasina. However, as per our experience working in the leprosy program, we know of many incidents in which there is discrimination against people affected by leprosy. But there is no formal recording or complaint system established yet. If the government passes the Anti-Discrimination Bill, this could encourage systems for complaints or recording of discriminatory cases for further action and to support the victims.

***Including leprosy into the Anti-Discriminatory Bill by the Government would result in establishing complaints mechanisms, recording and reporting systems, and inter-ministerial coordination to support victims of discrimination. This would assistance the Government in achieving zero leprosy discrimination.***

#### 4.4 Health (art. 25)

Paragraph 23 (a) of List of Issues

The Government has organized supply of anti-leprosy drugs in endemic areas (stratum 1 & 2) at Upazila level. But people are required to come to the Upazila level health point for confirmation and treatment. Among new leprosy cases detected each year, around 7-8% (250-300) are persons with disability due to leprosy (grade two disability) who do not have access to the assistive devices that they need. Besides, numbers of people suffer from leprosy complications and need hospital treatment. There are only three leprosy specialized hospital managed by the government giving

access for complication management. Other government secondary level hospitals are not experienced to deal with leprosy complication management.

***To reduce the burden of leprosy disability and improve access by persons needing hospital treatment for complication management, may possibly be strengthened and made available at secondary level government health points (medical college and district hospital, leprosy specialized hospital) by the Government. Resources could be allocated for assistive devices and disability service centre need capability to provide physiotherapy service for people with leprosy. Engaging frontline government health workers is vital for early new leprosy case finding and follow-up e.g. community clinic***

#### **4.5 Work and employment (art. 27)**

Paragraph 24 (b) of List of Issues

As per our observation and experience, there are some cases of people affected by leprosy losing jobs or income due to leprosy and the negative attitudes of employers. Some persons affected by leprosy are hiding their disease due to fear of losing their job.

***As part of zero leprosy discrimination, the Government may initiate complaints mechanisms (4.3 above) and information campaigns targeted at employers and ensure that leprosy cannot be used as grounds for dismissal. Anti-Discrimination Bill will be safeguarding for people with leprosy disability.***

#### **4.6 Adequate standard of living and social protection (art. 28)**

Paragraph 25 of List of Issues

The Bangladesh government is responsive and active towards supporting persons with disability. But in the Person with Disability Rights and Protection Act 2013, disability due to leprosy is not mentioned under the disability category. As a result, many persons with disability due to leprosy face difficulty or barriers to access social protection benefits. Leprosy is associated with stigma, so people affected by leprosy need social inclusion and mental support.

***The Government may well give priority to people affected by leprosy for social safety net services in order to create more social inclusion and improve their standard of living. The Government need to include disability due to leprosy as a separate category in collecting qualitative and quantitative disaggregated data on persons with disabilities.***

#### **4.7 Statistics and data collection (art. 31)**

Paragraph 28 (a) of List of Issues

***It will be beneficial if The Government include disability due to leprosy as a separate category in collecting qualitative and quantitative disaggregated data on persons with disabilities.***

#### **4.8 National implementation and monitoring (art. 33)**

Paragraph 33 (a) and (b) of List of Issues

***The Government may possibly take steps to ensure that persons with disability due to leprosy are included into the national level committees, for their voices to be heard and equal participation.***

***We would appeal to the Government to implement the Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members, to ensure protection and promotion of their rights and dignity of within the framework of the CRPD.***