

REPORT ON THE HUMAN RIGHTS SITUATION OF PERSONS AFFECTED BY LEPROSY IN PAKISTAN

Submitted for the consideration of the 19th Pre-Session of the CRPD Committee

Submitted by:
International Federation of Anti-Leprosy Associations (ILEP)
on behalf of four contributing organisations (listed in Section 1 below)

(The submission may be posted on the OHCHR website)

This submission is made by ILEP on behalf of a consortium of four organisations working towards the elimination of leprosy (or Hansen's disease) and towards fulfilment of the human rights of persons affected by this disease, in Pakistan and worldwide. Persons affected by leprosy play a significant participatory role in organisational decisions, particularly of the two Pakistan-based contributors.

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1. Contributors

This report is written jointly by four organizations committed to the fulfillment of the rights as citizens for persons affected by leprosy, as guaranteed in the CRPD. The organizations are:

- Marie Adelaide Medical Centre, located in Pakistan and founded in 1956, which, in addition to working for leprosy elimination in five endemic provinces, undertakes community based inclusive development programs for persons with disabilities. Its staff team has always comprised people affected by leprosy, especially at the operations level, and over time persons affected by leprosy have taken up senior decision-making positions. Children of leprosy-affected families are also working at both junior and senior level in the organization.
- Aid to Leprosy Patients Pakistan, located in Pakistan and founded in 1969, which provides medical and social assistance to people affected by leprosy across the country.
- Deutsche Lepra- und Tuberkulosehilfe (DAHAW), located in Germany and founded in 1957, which provides financial and technical support for leprosy programs in Pakistan.
- The International Federation of Anti-Leprosy Associations (ILEP), based in Switzerland, which is a federation of fourteen organizations with a shared vision of a world free from leprosy disease, leprosy-related disability, and leprosy-related stigma and discrimination.

2. Context

Following a very effective leprosy control program over the past 40 years, leprosy is in very slow decline in Pakistan. 250-350 new patients are diagnosed every year, 40% of them from Sindh province. Most patients are cured through successful drug treatment with minimal impact on their lives and families, but around 15% of new cases have visible impairments (typically to hands, feet or eyes) at the time of diagnosis. This is a sure indication of late detection of leprosy, which in turn indicates low awareness of the disease among health providers and in the community, and ongoing stigmatisation related to leprosy. As many as 50% of patients develop leprosy-related impairments later in their lifespan because of nerve damage caused by leprosy.

According to the 2019 census, 6.2% of the population (i.e. around 14 million people) are living with disabilities. Their socio-economic status is below average: the majority cannot claim their rights and entitlements, and stigmatization is still prevalent. Basic health, education and livelihood facilities are not easily accessible. Because of attitudinal problems in society and a lack of disability-friendly

facilities, many drop out in the early levels of education. Special education centres are few and normally far away from rural areas. Specialised rehabilitation facilities like orthopaedic centres, physiotherapy centres, audiology and speech therapy centres and mental health facilities are not available outside the big cities. Assistive devices are costly and not funded by the Government, and public transport is limited and/or inaccessible. Many persons with disabilities in rural areas, especially in low-income families, are confined to their houses because there are no means of mobility. Accessibility in terms of ramps, side supports, accessible washrooms and special transport is almost out of the question in rural areas, and only partially available in big cities.

As an example of good practice, it is noted that in Sindh province, the Government has established a separate department to look after the rights/needs of persons with disabilities, including assistive devices, inclusive education, accessible transport and quota for job placement.

Pakistan ratified the CRPD Convention in 2011 and subsequently adopted policies to ensure provision of the services that persons with disabilities are entitled to in line with the convention. Following the devolution of administrative power, provinces have also enacted laws to protect the rights of persons with disabilities. As a result, there are some improvements to the overall situation for persons with disabilities. But these policies and laws fail to explicitly mention disability caused by leprosy. Accordingly, for persons affected by leprosy, conditions remain the same, with ongoing daily experience of activity limitation and also participation restriction due to stigma.

3. Definition of disability

Article 1 of the CRPD Convention states that persons with disabilities include ‘those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.’ This definition very precisely matches the reality of persons who through leprosy have experienced nerve damage, leading to damage to hands, eyes or feet, and who as a result of both the impairments and negative societal attitudes are unable to fully participate in society.

However, persons with disabilities caused by leprosy are generally unable to access the rights and entitlements guaranteed by Pakistan’s adoption of the Convention. This is because the prevalent guidelines including the process for certification of persons with disabilities do not explicitly mention leprosy as a major cause of disability (especially considering the combination of leprosy-related impairments with attached societal stigma) with due weightage. As a result, persons affected by leprosy do not get the social benefits that people with disabilities usually get in Pakistan.

Recommendation:

In line with CRPD Convention Article 1, the Government is requested to amend the definition of disability in all relevant legislation, guidelines and policies to provide that all persons experiencing loss of sensation and/or with disabilities or deformities of hands, feet or eyes, as a consequence of leprosy, are entitled to the benefits mentioned in the existing policies for people with disabilities.

4. Discriminatory laws

Laws that discriminate against persons affected by leprosy remain on the Pakistan statute books. Examples are Dissolution of Muslim Marriages Act 1939, in which s.2(vii) allows dissolution if a husband has leprosy; and Pakistan Fish Inspection and Quality Control Act 1997, in which s.8 bars persons with leprosy from working in fish handling.

Recommendation:

In line with CRPD Convention Article 4(1b), the Government is requested to:

- Repeal or amend the discriminatory sections of the above Acts; and
- Review the Pakistan Code to identify and repeal or amend any other legislation that discriminates against persons affected by leprosy.

5. Awareness

In Pakistan, there is persistent societal stigma and discrimination related to disability and leprosy. Due to cultural beliefs and misconceptions, people in many areas still believe that disability is a curse of God. Persons with disabilities face difficulties in their daily lives, and invisible barriers to access to information, health facilities, education, jobs, equal participation in society and citizen rights. Studies in Pakistan highlight the urgent need for targeted awareness campaigns to dispel myths surrounding disabilities, and also around leprosy, to reduce this discrimination.

Recommendation:

In line with CRPD Convention Article 8, the Government is requested to initiate and maintain effective public awareness campaigns designed to counter the myths around disability and leprosy and to promote positive perceptions. In particular, social media should be an integral part of these campaigns.

6. Assistive devices

Assistive devices for rehabilitation (such as orthopaedic shoes, artificial limbs, callipers, wheelchairs, hearing devices, spectacles etc.) are costly and in most areas they are not made freely available by the Government for persons with disabilities. Many persons with disabilities in rural areas, especially in low-income households, are confined to their houses because of the unavailability of devices for mobility. Artificial limb centres do exist in Pakistan, but only in major cities.

Recommendation:

In line with CRPD Convention Articles 20 and 26.3, the Government is requested to make high-quality assistive devices freely available for persons with all types of disability, to ensure their mobility, their inclusion in society, and their capacity to participate in employment, education and all forms of community life on the same basis as the general population.

7. Health

Article 25 of the CRPD Convention obliges governments to provide persons with disabilities with the same range, quality and standard of healthcare as provided to other persons, and to ensure through training and standard setting that health providers are aware of the human rights, dignity, autonomy and needs of persons with disabilities, including persons affected by leprosy. However in Pakistan, persons with disabilities are liable to be stigmatised by healthcare personnel, and not provided adequate services, due to widespread lack of awareness and understanding of the needs of persons with disabilities.

Recommendation:

In line with CRPD Convention Article 25, the Government is requested to initiate regular awareness and training programs, targeted at general healthcare workers at all levels, to dispel myths and false beliefs among health staff about disabilities and leprosy and to ensure that persons with disabilities and persons affected by leprosy can access health services on an equal basis with others.

8. Education

In many places, cured leprosy patients and their families are living in the same communities and their children are studying in mainstream schools without any discrimination arising from a parental

history of leprosy. However, for children with disabilities, the position is more severe. Owing to their disability and attitudinal problems from society, many of them drop out in the early levels of education. Skills training, aiming towards full inclusion and empowerment, is essential to enable these persons to at least partly compensate for the lack of education.

Moreover, for children with disabilities including the relatively small number who are disabled due to leprosy, the official preference is for special schools. Special schools, however, are sparse nationwide, especially in rural areas.

Recommendation:

In line with CRPD Convention Articles 24(2), 9(1a) and 24(3), the Government is requested to:

- Shift its focus increasingly towards inclusive education instead of special education, thus enabling children with disabilities to attend schools near to their place of residence and in common with other children in the area;
- Ensure the identification and elimination of barriers to physical accessibility within schools; and
- Establish skills training centres for persons with disabilities, including persons affected by leprosy, and particularly those who were unable to complete their education.

9. Work and employment

The economic standing of persons with disabilities, including persons affected by leprosy, is significantly below the rest of the population. For them, livelihoods – especially accessing paid work – are a major challenge because of lack of awareness by employers, lack of acceptance by other employees, and lack of accessibility within the workplace.

Recommendation:

In line with CRPD Convention Article 27, the Government is requested to:

- Ensure access by persons with disabilities, including persons affected by leprosy, to general technical and vocational guidance programs, placement services and vocational and continuing training;
- Promote the employment of persons with disabilities, including leprosy, through awareness campaigns directed at employers (including within the public sector) and the general population, along with other appropriate policies and measures; and
- As a complement to programs targeted at obtaining employment in the public or private sectors, undertake special programs with persons with disabilities, including persons affected by leprosy, aimed at self-employment including access to livelihoods-related loans.

10. UN Principles and Guidelines:

Principles and Guidelines for the Elimination of Discrimination Against Persons Affected by Leprosy and their Family Members were adopted by the UN Human Rights Council in 2010, and by the UN General Assembly in 2011. Broadly mirroring the structure of the CRPD Convention, they provide a valuable roadmap for states to meet and clarify their obligations under international human rights law through policy frameworks that protect the rights of persons affected by leprosy.

Implementation of the Principles and Guidelines is also urged in the WHO Global Leprosy Strategy 2021-2030, as a significant contribution to enabling persons affected by leprosy to live with dignity.

Recommendation:

The Government is requested to use the Principles and Guidelines to stimulate actions to combat prejudice and discrimination, including actions to promote a better understanding of leprosy among community and religious leaders and people employed in healthcare, education and social services.